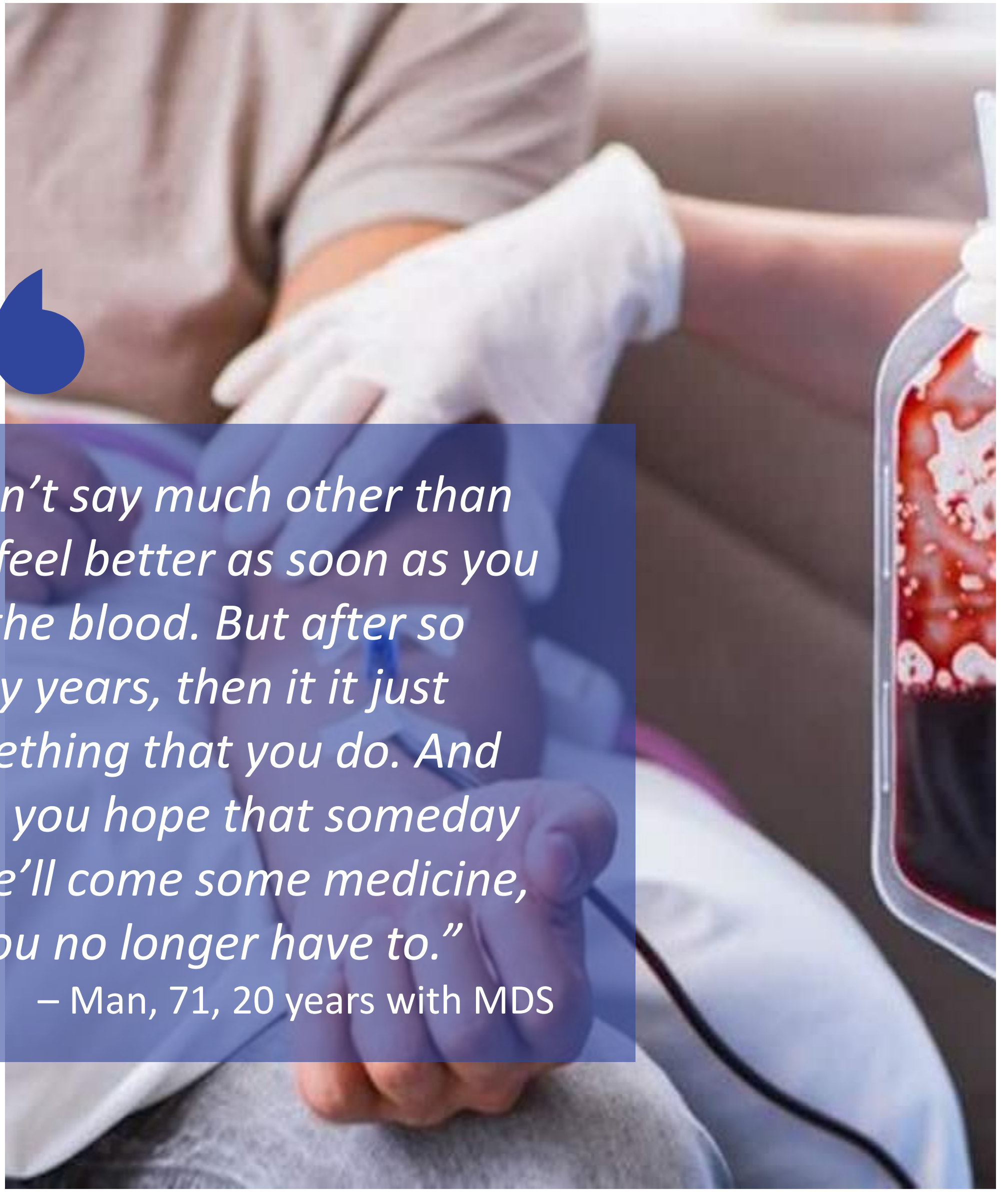
MDS & B-THAL PATIENT INSIGHTS IN THE NORDICS

Country report: Denmark

Stefan Papadakis
19 September, 2020

GAME CHANGERS



> *"I can't say much other than you feel better as soon as you get the blood. But after so many years, then it it just something that you do. And then you hope that someday there'll come some medicine, so you no longer have to."*
>
> – Man, 71, 20 years with MDS

Contents

INTRODUCTION & BACKGROUND

A closer look at the objectives and our approach

INTRODUCTION & BACKGROUND
AN OVERVIEW OF THE MARKET RESEARCH

Target group

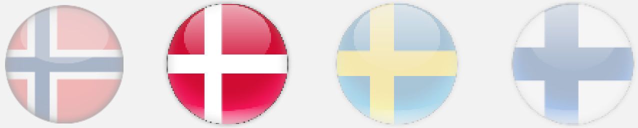
Patients diagnosed with **low risk MDS or beta-thalassemia** who are undergoing regular blood transfusions; receiving at least 2 units pr. 8 weeks.

Sample

28 patients in total:

- 6 MDS and 3 B-thal patients in Norway
- **8 MDS and 0 B-thal patients in Denmark**
- 4 MDS and 2 B-thal patients in Sweden
- 5 MDS and 0 B-thal patients in Finland

Geography



Norway **Denmark** Sweden Finland

Fieldwork Design

The interviews were conducted as in-depth **telephone interviews** for the **duration of 60 minutes.**

Research team

Stefan Papadakis, Denmark
Maria Hedengren & Jessica Rustas-Robin, Sweden
Alexandra Brendan, Norway
Harri Kyttälä & Elina Sydänmaanlakka, Finland

Fieldwork period

Norway: May 4th to June 30th, 2020
Denmark: March 23rd to September 17th, 2020
Sweden: August 18th to October 30th, 2020
Finland: April 29th to October 2nd ,2020

INTRODUCTION AND BACKGROUND

A QUALITATIVE RESEARCH DESIGN

IN-DEPTH INTERVIEWS

The chosen methodology for this study is in-depth interviews to create a private and comfortable space to share individual and personal experiences.

VIA TELEPHONE

The in-depth interview were carried out via telephone to enable geographical spread and lower risks during the COVID-19 pandemic.

INTRODUCTION AND BACKGROUND
FRAMING NOTES FOR DANISH REPORT

In the ensuing pages we will unfold the patient universe and their blood transfusion experiences. **To understand the potential biases of these findings, we recommend to have the following framing notes in mind**:

- The patient recruitment went solely through the patient organization for lymphoma and leukaemia patients (LyLe), also covering other haematological indications such as MDS. **All patients in this research are thus members of a patient organization** and one could thus hypothesize that the patients included have more general support and are more well-informed than those patients not organized – although this study cannot confirm this hypothesis.
  - B-thalassemia patients are not organized within LyLe and therefore this patient group is not included in this study.
- Although we recruited patients with the intention of having a range of diversifying splits (see note on recruitment in appendix) a pragmatic approach has meant that some **sample considerations** need to be held in mind:
  - Generally, and naturally, the patients **tend to be elderly (68-80**), a few with blurring co-morbidities.
  - Most patients (6/8) are **retired** implying that the temporal impact of blood transfusions are less significant.
  - All respondents **live relatively close** (10 min to appx. 1 hours) to the hospitals where they receive blood transfusions, limiting the impact of travel.

LIVING WITH MDS:
PATIENT UNDERSTANDING

Insights into the how patients experience living with MDS and how they perceive and approach their diagnosis

FRAMING QUOTE OF THE SECTION

> **“It is invisible, so people can’t understand it. People always tell me “you look good!”. I hate it when they say that because I feel like a 100-year old inside.”**

MDS patient #3, 71 y/o woman, 6 years with MDS 🇩🇰

LIVING WITH MDS
DIFFERENCES IN DISEASE IMPACT & PERCEPTIONS

Before going into details about living with MDS, it is important to note that there is a **variety in the disease perceptions, approaches and impacts across the patient sample,** possibly due to the syndromatic character of MDS.

- First off, we should note that **patients have different disease expressions**: most but not all are anaemic whereas a few also – or exclusively – suffer from neutropenia and thrombocytopenia, naturally shaping their experience and the impact MDS has on their lives.
- The impact of these three syndrome expressions also vary as patients are in different stages of their disease.
  - Also, patients seem to settle on different blood percentage (BP) levels, implying some differences in the treatment standard. Patients thus manage their disease differently and periodically live with lower levels than others.
  - The effect of anaemia, at least as disclosed to us, also seem to differ where some experience constant fatigue; whereas others only periodically.
- The perceived severity of the disease also splits the sample, where the **number of years with the diagnose seems to have an influence on perceptions**, where patients come to terms with their diagnosis and become more relaxed on the potential severity as the disease progress is experienced as slow.

LIVING WITH MDS
PERCEIVED IMPACT VARIES

“I don’t feel anything, I don’t think about it, I don’t think it is dangerous. I just get the blood I need and then I feel fine”.

MDS Patient #7, 72 y/o woman,
4 years with MDS

“There is a lot of things you can’t do anymore. Or at least you would have to do them very slowly to not get too tired. Generally you become tired and sluggish.”

MDS Patient #2, 71 y/o man,
14 years with MDS

LIVING WITH MDS
DISEASE HISTORY SHAPE PERCEPTIONS

> “My life has changed totally. I used to be independent, engaged and extroverted. I am not anymore. I feel like a parenthesis.”

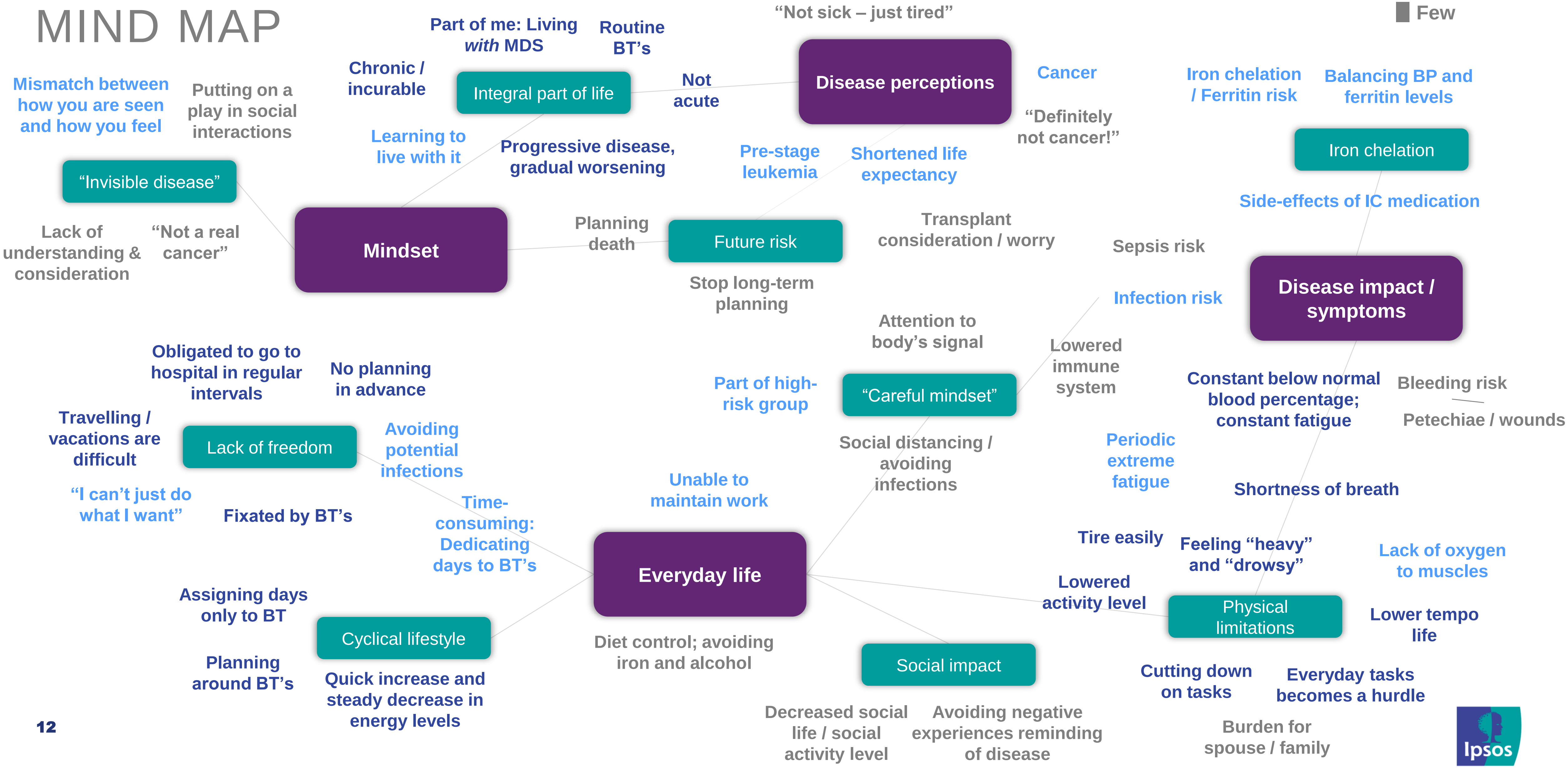
**MDS Patient #8, 80 y/o woman,
1,5 year with MDS**

> “It is just part of my life, so I do not have that many thoughts about it. It is just there, right? It lives with me, and I live with it. And we try to make the best of it together.

**MDS Patient #1, 68 y/o woman
20 years with MDS**

LIVING WITH MDS
MIND MAP

■ All or most
■ Common
■ Few



Mindset

“Invisible disease”

Mismatch between how you are seen and how you feel

Putting on a play in social interactions

Lack of understanding & consideration

“Not a real cancer”

Integral part of life

Chronic / incurable

Part of me: Living *with* MDS

Routine BT’s

Learning to live with it

Progressive disease, gradual worsening

Not acute

Planning death

Future risk

Stop long-term planning

Pre-stage leukemia

Shortened life expectancy

Transplant consideration / worry

Disease perceptions

“Not sick – just tired”

Cancer

“Definitely not cancer!”

Disease impact / symptoms

Iron chelation

Iron chelation / Ferritin risk

Balancing BP and ferritin levels

Side-effects of IC medication

Sepsis risk

Infection risk

Lowered immune system

“Careful mindset”

Attention to body’s signal

Part of high-risk group

Social distancing / avoiding infections

Constant below normal blood percentage; constant fatigue

Bleeding risk

Petechiae / wounds

Periodic extreme fatigue

Shortness of breath

Tire easily

Feeling “heavy” and “drowsy”

Lack of oxygen to muscles

Everyday life

Lack of freedom

Obligated to go to hospital in regular intervals

No planning in advance

Travelling / vacations are difficult

Avoiding potential infections

“I can’t just do what I want”

Fixated by BT’s

Time-consuming: Dedicating days to BT’s

Unable to maintain work

Cyclical lifestyle

Assigning days only to BT

Planning around BT’s

Quick increase and steady decrease in energy levels

Diet control; avoiding iron and alcohol

Physical limitations

Lowered activity level

Lower tempo life

Cutting down on tasks

Everyday tasks becomes a hurdle

Burden for spouse / family

Social impact

Decreased social life / social activity level

Avoiding negative experiences reminding of disease

MDS PERCEPTIONS
A CHRONIC AND PROGRESSIVE DISEASE

Discussing MDS with the patients, the following disease perceptions come across:

- MDS is considered a **chronic disease** that patients *die of* or *live with* for the rest of their lives. The only cure is a bone marrow transplantation that comes with a very high mortality rate along other severe risks, and that patients in this sample are very hesitant to even consider.
- MDS is also considered a **progressive disease**, where the ability to produce healthy and mature blood cells decrease gradually; simultaneously also gradually increasing the blood transfusion frequency and dependency.
  - The MDS diagnosis for most patients also come with the **potential risk of progressing into acute leukemia.** This is reflected in the mindset of the patients as a future risk and distant fear, that impacts certain aspects of their lives. Many patients seem to be given a 5-year life expectancy, but as the years pass beyond the expected, patients seem to come more to terms with their diagnosis.
  - The disease perception of **whether MDS is cancer, a pre-stage leukemia or not cancer at all however differ across the sample,** where a few patients actively call it cancer and a few in the other end of the spectrum are adamant it is not.
- Generally, there also seem **a lack of standard in how specialists frame MDS towards the patients**, with differences in the information given and disease knowledge patients have.

THE MDS MINDSET
AN INVISIBLE PART OF ME

The chronic and incurable fact of MDS is visible in the mindset apparent in most MDS patients:

- First off, we see a tendency for those who have lived with MDS for a couple of years to consider it **a natural and integral part of themselves and their lives**. The patients generally seem to internalize and find a normality in their lives with MDS and the implications it entails after a couple of years.
  - The normalization also means that **blood transfusion tend to become a routine task,** not requiring much thought.
- In the first phases of living with their diagnosis, many patients are either told or read themselves that the **life expectancy of MDS patients are appx 5 years from the diagnosis**. This shapes the mindset among patients as some patients tell of planning deaths, creating wills while trying to live life to the fullest and, importantly, avoid long-term planning.
- Another key aspect of the disease shaping the mindset and experiences of the patients is that it is considered **an invisible disease.** For some, it is difficult to manage having a severe diagnosis, but at the same time not being visibly ill. This may result in **feelings of lacking understanding and consideration from others** – including family members, that some patient struggle with – especially when they are at their lowest energy level in the BT cycles.

DISEASE IMPACT
FATIGUE & INFECTION RISK

MDS results in a lot of direct medical impacts shaping how the lives of the MDS patients are impacted:

- The most common expression of MDS is lack of red blood cells and almost all patients in this sample are anaemic. Being anaemic means a low haemoglobin level which limits the transport of oxygen in the body. This has numerous impacts for the way of life for the MDS patients:
  - All anaemic patients highlight the **feeling of fatigue as the main impact of MDS,** although the severity differs**.** They live with constant subnormal haemoglobin levels which results in **a series of physical limitations affecting multiple aspects of their lives**; from habitual tasks and house chores to their social activity level.
  - To counteract the low haemoglobin levels, patients are given blood transfusions when the level drops below a certain level (around 5 or 6 for most), at somewhat regular intervals. The transfusions increase the BP level to an individualized level – but still below normal level – only to gradually decrease up until the next transfusion. This means that **patients live a cyclical life with constant fatigue that is becoming more and more outspoken** up until it is time for the next blood transfusion.
- For the neutropenic MDS patients with lower levels of white blood cells (neutrocytes), there is a constant **infection risk** that need to be kept in mind in most aspects of their lives: family life, social interactions, transport and more.
- A few thrombocytopenic patients in this sample suffer from lower levels of blood platelets (thrombocytes), which entails an **increased bleeding risk,** which results in a withholding lifestyle where risky situations and intense exercise (risk of internal bleeding) are to be avoided.

IMPACT ON WAY OF LIFE

PHYSICAL AND SOCIAL LIMITATIONS

The symptoms and treatment of MDS result in a number of physical and social limitations affecting the lives of the patients.

- Due to the below normal haemoglobin level, anaemic patients suffer from a **constant or at least cyclical fatigue**.
  - This low haemoglobin level also have **general physical limitations**, where once everyday tasks can become burdensome, as well as patients may find it difficult to exercise and participate in physical activities as they tire easily and quickly experience shortness of breath. Generally MDS patients express that they may **feel “heavy” and “drowsy” at times and live life at a lower tempo;** leading to a life with lowered overall activity level.
  - This lowered activity level also spill-over into **a lowered social activity level**, where many MDS patients do not have the energy to be active in organizational or associational activities; on top of limiting physical social activities.
  - Especially at the end of blood transfusion cycle, when their BP are at the lowest, the patients tend to cut out activities and plans.
- The neutropenic patients have an extra set of limitations as they also have to worry about an increased infection risk.
  - This implies **avoiding exposure to potentially ill people**, which increases limitations on the social activities further as patients reveal having to avoid public transport, buffets and other risk situations, as well as staying-in during flu season and not seeing family, friends and grandchildren when they have a slight illness. With COVID-19 the social distancing and limitations have increased further for these patients.

LIVING WITH MDS
MDS AFFECTS MULTIPLE PARTS OF THE PATIENTS' LIVES

Everyday/family life

Patients tire easily, limit physical activities.

Fatigue and physical limitations makes some **unable to take care of everyday tasks in the household.** This causes some worry about being a burden to their spouse.

Infection risk for neutropenic patients can limit visits from grandchildren.

Social life

Many patients lack the energy to maintain the social life they had before MDS and **generally report a decrease in social activities**. Especially, but not exclusively, those entailing physical activity.

Neutropenic patients are further limited socially due to an increased infection risk.

Work life

MDS patients diagnosed in while active in the workforce, mostly report having **difficulties maintaining their jobs** and getting offered early retirement.

Two in the sample however still work; but with some adaptions and limitations.

Leisure

Lack of energy for exercise and physical activities.

The cyclical BT **limits travel,** causing a decrease in QoL for the retired MDS patients.

The hospitalization risk limits the number of destinations considered safe.

General the necessary BT's are considered fixating and providing a **lack of freedom**.

Key implications of MDS

Direct symptomatic implications:

- Fatigue and easy tiring (anemia)
- Infection risk (neutropenia)
- bleeding risk (thrombocytopenia)

Physical shortcomings and limitations:

- Burden to do everyday tasks
- Tire easily, shortness of breath
- Cut down activities, low tempo

Social limitations & restrictions:

- Social distancing (infection risk)
- Lowered social activity level

Planning restrictions & considerations:

- Fixated by blood transfusion limiting e.g. travel
- Setting a side 1-2 full days pr. 2-4 weeks.
- Limiting activites further at end of interval.

Medical side-effects:

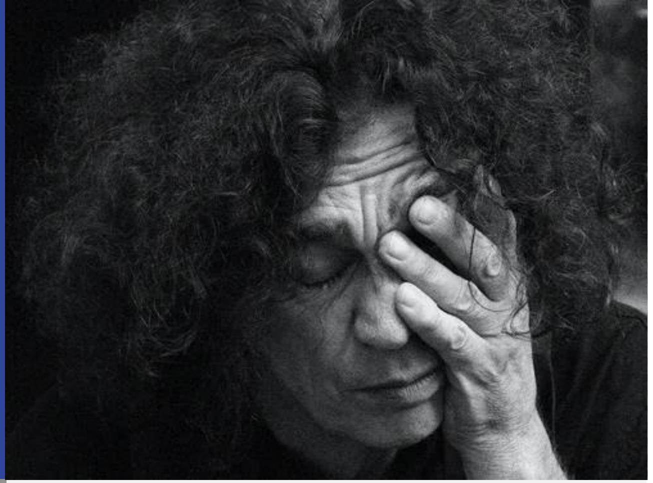
- Iron chelation medicine, particularly

Mental side-effects:

- Risk of disease progression
- Invisible disease; lacking understanding
- Feeling a burden to spouse (few)
- Lacking forum to talk about disease.

”I am not able to do all the things I want. The tiredness is a disability.”

MDS patient #5, Woman, 75 y/o



“I can easily catch an infection and therefore I’m mindful about the tings I should avoid. I would never go to the cinema during Flu season.”

MDS patient #1, Woman, 68 y/o

“The transfusion days are blocked in my calendar for the entire year. On these days I can not schedule anything else.“

MDS Patient #2, Man, 71 y/o

LIVING WITH MDS
QUOTES

“Today I cannot even dream of doing all the things I am used to. My physical condition is not good enough.”

- MDS Patient #8 Women, 80 years

“We used to travel a lot all around the world. I wish we could continue doing that, but it is a limitation that we can only be out for 10 days.”

- MDS Patient #2, Man, 71 years

“We still do family gatherings, but everybody bears my diagnosis in mind. If someone has a cold they stay away”

- MDS Patient #4, Man, 75 years

“In the period right after I was diagnosed with MDS I refused to go to the dentist. Why should I if I would anyway end up dying two years later? Now 6 years later I am convinced that I will not die from the disease, but I will live with it for the rest of my life.”

- MDS Patient #3, Woman, 71 years

PATIENT JOURNEY

History and interactions that shape the patient perceptions

PATIENT JOURNEY

“I have become more and more dependent of the blood transfusions during the years. The only way I can be cured is via a bone marrow transplant, but the mortality rate is 25%”

MDS patient #1, Woman, 68 years, 20 years with diagnosis

PATIENT JOURNEY
THE TYPICAL MDS PATIENT JOURNEY

Pre-diagnosis

Patients begin to feel more **fatigue.** Often this is a hindsight awareness since the patients have blamed it on other causes such as natural ageing.

Some patients live with the increased weariness for several years before the diagnosis is stated.

Discovery

A few patients consult their healthcare provider on behalf of the weariness. Some patients visit their doctor for a a routine check and some patients end up at the hospital - either for other reasons or due to a collapse. Often the discovery is a result of eliminating diseases.

Similar for all patients is a blood test with an (alarmingly) **low haemoglobin level** as the first stage of the discovery. The patients receive **iron** or **B12 vitamin tablets,** but the tablets causes low or no effect.

Diagnosis

A **bone marrow biopsy** is needed to state the diagnosis. Additional waiting time before final judgment of stage of the disease (i.e.. Low Risk/High Risk)

The patients receive **limited oral information** about the disease. Most patients continue the information search themself.

Based on the way the initial discovery happened (i.e. routine check vs urgent hospital admission) the patients experience the diagnosis process either as dramatic or as slow and lengthy.

Initiation

EPO/Aranesp injections are initiated to help the patients increase their natural production of blood cells.

For patients with a very critical haemoglobin level blood transfusions are initiated immediately with high frequency.

The medical treatment and follow-up are handled by the hospital/haematologist.

Blood transfusion

Blood transfusions are initiated upon **low or no-response to EPO/Aranesp**. Mostly within a few months from diagnosis.

Blood test before the transfusion to ensure the right type and amount of blood. Most patients prefer to get blood test the day before the transfusion in order to safe time on the hospital.

Monitoring of physical condition and possible allergic reaction during transfusion. Medical staff are perceived friendly.

Few patients receive **Vidaza** concurrently with the transfusions for shorter or longer periods.

"Normality"

Over time the blood transfusions becomes normalized and a part of the patients' everyday routines.

Many patients experience a gradual worsening causing more frequent transfusions and more units pr. transfusion.

The increased amount of blood generate an **iron chelation risk** which forces the patients to take medicine (e.g. Exjade, Ferriprox) causing many side-effects

Progression?

The patients are aware of the risk of the disease evolving to acute leukemia. For many patients this is not a present subject of matter.

None of the patients consider bone marrow transplantation due to the very high risk affiliated and due to their current stage of the MDS-disease.

PATIENT JOURNEY
FINDING NORMALITY, BUT ALSO SLOWLY PROGRESSING

Generally, the MDS patients follow the same journey as outlined in the previous slide. Importantly, it is worth noting that the sample today mostly find themselves in a phase of normality, living *a life with MDS.*

- Getting the **MDS diagnosis is mostly a long process of eliminating other possible explanations for their initial symptoms**; e.g. fatigue, shortness of breath, leading to some expressing **a relieve when finally receiving their diagnosis**. For a few, however, the diagnosis is more dramatic with fainting, sudden crashes and a very acute hospitalization. **In hindsight many acknowledge that they must have suffered from low haemoglobin levels for a long period before their diagnosis –** often blaming on natural causes and ageing.
  - Further, MDS patients are diagnosed at the end of their working years or later, having all lived a normal life prior to their disease. The MDS impact thus feels as a loss of health.
- Currently, patients cope with the impacts of MDS discussed in the previous section, and having to go to blood transfusions at regular intervals (every 2-4 weeks). But those with a couple of years of disease history seem to cope well with their diagnosis, adjusting their lives to the disease, **routinizing the transfusions and finding a normality**.
- Patients experience a **gradual worsening; over the years requiring more blood units and blood transfusion more often -** reminding them of the future progression risk.

PATIENT JOURNEY
QUOTES JOURNEY

"I was not negatively affected by getting diagnosed with MDS. After a long period with anemia and doctors rejecting different possible diagnosis, it is satisfying finally to know what is wrong."

- MDS Patient #7, Woman, 72 years

"Nobody told me that the disease is variety of cancer. I figured that out myself two months later."

- MDS Patient #4, Man, 73 years

"The worst part is that it can turn into acute leukemia. It develops that way for many... "

- MDS Patient #2, Man, 71 years

"We were traveling in Bali, and then one day I suddenly collapsed. I had felt tired and fatigued through the entire vacation, and I could not explain it. Now I am sure that I have been carrying the disease for a long period of time without noticing."

- MDS Patient #8 Women, 80 years

PATIENT SUPPORT NEEDS

PATIENT SUPPORT NEEDS

> **“I would really like to meet with other MDS-patients from my area. I have searched for them, but there is no one. People have other sorts of diseases.”**

MDS patient #3, Woman, 71 years, 6 years with diagnosis

PATIENT SUPPORT NEEDS
A WISH TO HEAR FROM OTHER PATIENTS

- The family members act as the main support for many of the patients in helping understand the disease.
  - A few patients, however, experience a lack of understanding from family and friends because of the hidden characteristic of the disease.
- Most patients have some **interest in talking to patients in same situation** but have difficulties finding others due to MDS being a rare diagnosis.
- Patients feel safe with the specialized doctors and there is a **high satisfaction with the treatment** from the nurses or med. students during blood transfusions.
  - There are few other interactions with the health care system for their MDS, and most have no other treatment, so the BT sessions also provides a sense of being taken care of.
- Many patients express searching for more information about MDS after their diagnosis, and it also seems that the information received from the hospital in the beginning is **limited and lacking standards.**
  - Especially the information about severity of the diseases (i.e. blood cancer or not) seem to differ.

KEY PATIENT SUPPORT NEEDS

- Information about living with MDS; not just medical information. Especially in the first 1-2 years of their journey or when crossing milestones.
  - Patient-to-patient interactions are enquired. A need for talking to patients in the same situation.
- Help to articulate and discuss their diagnosis to increase understanding from others.
  - Patients find it difficult balancing not wanted to be labelled sick, but at the same time seeking understanding for their physical and social limitations.
- Access to everyday support, helping in daily activities. And social activities suitable for their energy levels.

Note that patients were recruited via the patient organization LyLe, thus already having access to their support.

PATIENT SUPPORT NEEDS
QUOTES

“People like us with hidden diseases should wear a green dot on our foreheads. Then people could show us a bit of consideration.”

- MDS Patient #3, Woman, 71 years

“I feel like I can take care of myself, I do not need a patient group. I have a very good support from my wife and my daughter.”

- MDS Patient #4, Man, 73 years

“I really want to get to know other people with the disease. That is a great desire for me.”

- MDS Patient #8, Woman, 80 years

“It is really nice to be able to discuss illness without people thinking ‘now she talks about her illness again’. Because I do not want to be the one who always does that. But at the Lyle meetings I am ask how I feel and how things are going, and you hear the same from others.”

- MDS Patient #7, Woman, 72 years

THE BLOOD TRANSFUSION EXPERIENCE

How patients experience disease treatment with a detailed deep-dive on blood transfusions

FRAMING QUOTE OF THE SECTION

“The day after my blood test I hurry to sundhed.dk to see if I need 2 or 3 units of blood. I prefer as few [blood units] as possible, so I get as little ferritin as possible!”

MDS patient #1, 68 y/o woman, 20 years with MDS

THE BLOOD TRANSFUSION EXPERIENCE

THE TRANSFUSION CYCLE

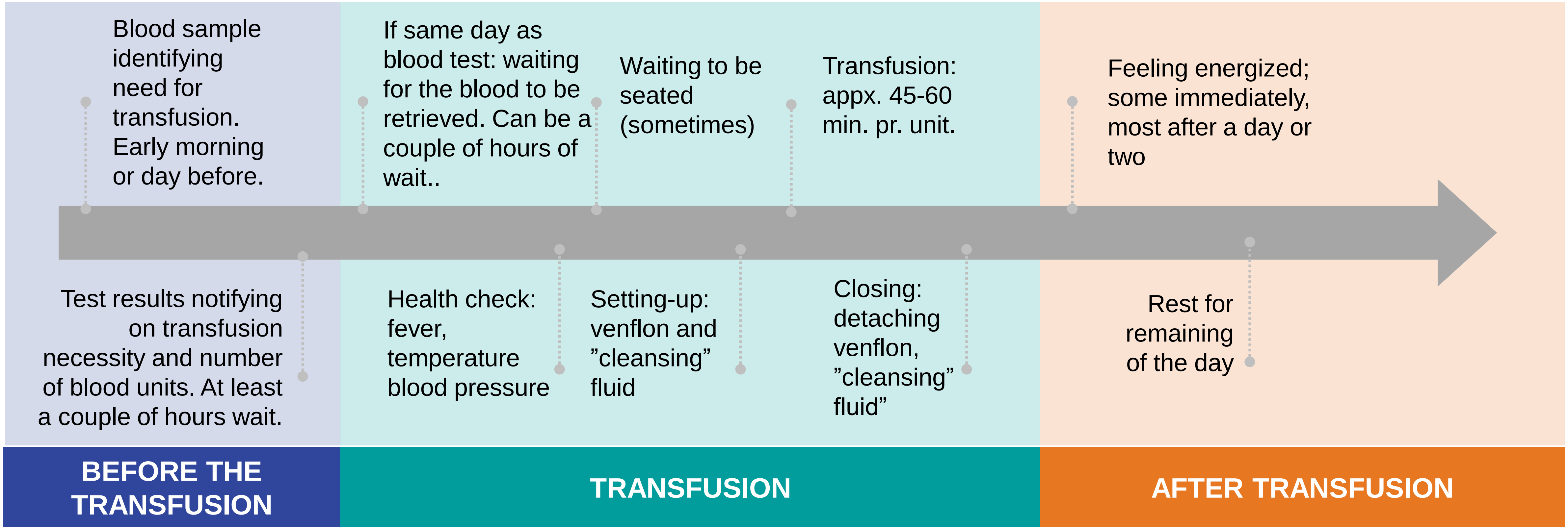
Patients undergo blood transfusions when their haemoglobin level reaches an individually set level of acceptable functionality (often around 5 or 6). This level is often reached at regular intervals every 2-4 weeks, with the frequency gradually increasing over the years. All patients relatively close to their transfusion hospitals limiting the impact of travel.

“Normal period” 2-4 weeks	**“Low energy”** 2-3 days	**Transfusion** 1-2 days	**“Energizing”** 1-4 days
• “Normal” life with MDS; with subnormal haemoglobin level. • Acceptable functionality and activity level. • Gradual decrease in haemoglobin levels.	• Lower haemoglobin level and lowed functionality • Decrease social activity level; some avoiding plans altogether. • Looking forward to getting new blood and energy.	• Full day at hospital, rest in the evening. Blood testing in morning or day before. • Ascribing entire day(s) to the transfusion. • Routine behaviour. • If many units, transfusion may take two days.	• Feeling good and energized. Effect felt immediately or in the first few days. • Some normalization of this feeling over time. • Increasing activity level to normality..

THE BLOOD TRANSFUSION EXPERIENCE

STEPS IN THE TRANSFUSION PROCESS

Blood transfusion consists of two main parts: a blood sample test identifying the need and the actual transfusion. This can be done either the day before or in the morning prior to the transfusion. **Patients ascribe the full day(s) to transfusion**.



Blood sample identifying need for transfusion. Early morning or day before.

Test results notifying on transfusion necessity and number of blood units. At least a couple of hours wait.

If same day as blood test: waiting for the blood to be retrieved. Can be a couple of hours of wait..

Health check: fever, temperature blood pressure

Waiting to be seated (sometimes)

Setting-up: venflon and ”cleansing” fluid

Transfusion: appx. 45-60 min. pr. unit.

Closing: detaching venflon, ”cleansing” fluid”

Feeling energized; some immediately, most after a day or two

Rest for remaining of the day

BEFORE THE TRANSFUSION

TRANSFUSION

AFTER TRANSFUSION

TREATMENT & MANAGEMENT
QUOTES ON THE BLOOD TRANSFUSION EXPERIENCE

	BEFORE THE BLOOD TRANSFUSION	DURING THE BLOOD TRANSFUSION	AFTER THE BLOOD TRANSFUSION
#8, Woman 80 y/o, 1,5 year, 2-week interval	“I look forward to it because it is both pleasant and good for me. I need it and it helps me.”	“It is a day of celebration. They are so nice. You are expected and you feel taken care of.”	“I can feel a couple of days later, or maybe even the same day, that I feel better.”
#7, Woman 72 y/o, 4 years, 4-week interval	“I am a bit tired and need to be a bit more careful, because I am not able to do that much. So I just take it easy and wait until it is time to go to the transfusion..”	“I have no problems with it at all. The doctors are nice, and I can talk to the other patients, if they like it. It is painless – besides the pinprick, which is nothing to talk about.”	“You can feel it immediately – now your muscles don’t hurt anymore. Your cheeks can blush. And even more so the day after, The result is really positive – you almost get a bit high.”
#2, Man 68 y/o, 20 years, 2-week interval	“By now you are used to the drill. It is not like you look forward to it – it is just something you do."	“I just assign the entire day to it, because you never know if it will drag out. And it’s something you have to do if you want to feel well.”	“You get better as soon as you get the blood. But after going it through for so many years, you don’t really notice it anymore.,”
#1, Woman 71 y/o, 15 years, 2-week interval	“It’s not something that worries me at all. Sometimes I might say, ‘now I am really happy to go, because then instead of crawling my way forward, then tomorrow I can walk.”	“I don’t think much about it. It is a part of my life – I just go there and get it.”	“When I receive blood transfusions then I also get a lot of ferritin in my body. And that is bad, because it may accumulate in the body and destroy my kidney, liver and other organs.,”

THE BLOOD TRANSFUSION EXPERIENCE

A PLEASANT EXPERIENCE; FEELING TAKEN CARE OF

The MDS patients in this sample have little negative to report on the actual blood transfusion experience:

- Importantly, there are **no or few worries about undergoing transfusion**; interestingly many say that they are not concerned about the blood being clean. Possibly a generational remark due to past concerns from back in the days.
  - The transfusions also seem to be **considered "routine behaviour"** as they take place at regular intervals over many years. The sessions are in that sense normalized as an inevitable part of life.
- Many patients also express **gratitude for the treatment, keeping them alive and able to live a somewhat normal life**. They are generally very thankful towards the personnel and the people donating blood.
- The experience itself is described as quite **relaxing and pleasant**. There is little or no pain and discomfort associated with the transfusion and they feel well taken care of.
  - The young and dedicated personnel is highlighted by most as "nice", "fantastic" or "amazing".
  - Despite the overall gratefulness with the hospitals' work and support, a few patients enquire more possibilities to talk to other patients during the blood transfusions and improving the setting; e.g. better chairs and sandwich etc.
- For many patients, the transfusions are their **only treatment for MDS as well their only face to face interaction with the health system and health care professionals for the MDS** – especially since the emergence of COVID-19. For many the transfusions thus provide a feeling of safety **functioning as a proof of being in treatment giving a feeling of being cared for.**

THE BLOOD TRANSFUSION EXPERIENCE

TRANSFUSIONS IS AN OBLIGATION LIMITING FREEDOM

Despite the worry-free and pleasant experience, the transfusions are still believed to limit the freedom of the patients.

- First off, the blood transfusions are considered **time-consuming**. Patients need to spend appx. 6-8 hours at the hospital in total for each transfusion, which evidently impacts their lives. When it is time for transfusion, patients ascribe the full day(s) only to the transfusion, pulling out these pages in the calendar.
  - However, as most are retired or have limited work, this is not perceived to have any large negative impact.
- **The main negative aspect of the blood transfusions is thus not the time spent, but the obligation of having to go at regular intervals**. This is for many experienced as a limitation on their freedom. The transfusions are paramount for their health and well-being and they cannot be skipped or postponed significantly.
  - This limitation of freedom has **concrete consequences in their planning of activities,** taking out the days for transfusion and often the days just before as well. But most significant for the patients in this sample is **being unable to travel for longer periods** as they have to go to the hospitals at relatively frequent intervals.
- Generally, being bound to transfusions at regular intervals is perceived as an decrease of their personal freedom and providing a negative impact of their life quality.
- Further, visiting the hospitals frequently also serve as a **negative reminder that they are ill** and are, in fact, patients.

THE BLOOD TRANSFUSION EXPERIENCE
NORMALIZATION AND ROUTINE

“It really does not affect my life that much. I just need to be mindful of it – just like when I need to get a haircut. Now it is about time”

MDS Patient #7, 72 y/o woman
4-week BT intervals

“It is what it is. It has become routine to me going to Herlev [hospital]. It is not like my neck hair rises or anything when we talk about it. I have come to terms with it. That is just the way it is.”

MDS Patient #1, 68 y/o woman
2-week BT intervals

THE BLOOD TRANSFUSION EXPERIENCE
BUT FIXATING AND OBLIGATING

“I am not able to go on vacation for more than 10 days since I need to be home for the blood transfusion every second week”

MDS Patient #2, 71 y/o man
2-week BT intervals

“Nobody wants to be at the hospital every second week. I am obligated to it. I am obligated by my disease. It is really annoying that I cannot just plan to travel for a month or so.”

MDS Patient #1, 68 y/o woman
2-week BT intervals

THE BLOOD TRANSFUSION EXPERIENCE
IRON ACCUMULATION & MEDICATION SIDE-EFFECTS

The overall **effect and result of the blood transfusion is perceived as positive**. But due to the iron accumulation effect, patients are forced to manage at lower than normal haemoglobin levels.

- Generally, the MDS patients look forward to the transfusions and its positive effect on their energy levels and well-being. The blood transfusion experience in itself is pleasant, and the patients experience a positive feeling of being energized and oxygen flowing to their muscles and cheeks after the transfusions.
- However, despite the positive effects of increasing the haemoglobin levels, **MDS patients still settle on an individualized level below normal**. The framing is that frequent blood transfusions have potential consequences – especially due to iron accumulation – and they are to kept at a minimum.
  - Therefore patients and their HCP’s thus spend some time **finding the right levels at which they are kept, where patients can lead a somewhat functioning life**, **while avoiding any excessive blood transfusions**. Some patients succeed in being managed at higher level than others, as they want to function on a certain level.
- This is especially due to the risk of iron accumulation, that most patients are aware of, potentially leading to fatal organ failure. To counteract iron accumulation and dangerous ferritin levels, patients are administered mitigating medication.
  - Exjade, in particular, is revealed to have multiple quality of life impacting side-effects, such as itching and nausea. The **iron accumulation and the mitigating medication thus present a very negative bi-effect of transfusion.**
- Further, a few patients also express a worry that receiving blood may slow down the bodies own production, **pushing them towards a negative disease progression** and future risk of leukaemia.

THE BLOOD TRANSFUSION EXPERIENCE

A BALANCING ACT BETWEEN A NORMAL HAEMOGLOBIN LEVEL AND THE RISK OF IRON ACCUMULATION

> “You should neither get too much blood – that isn’t good either. So we try to maintain a good rhythm, not risking to much ferritin in the blood. You need to find level where you don’t risk suffering from something else!”
>
> **MDS patient #7, 72 y/o woman**

> “I’ve always said, that if I am to maintain a normal functioning life, then I need a decent BP level. But it always become a compromise, because it results in high ferritin levels, which you then need to remove.”
>
> **MDS Patient #2, 71 y/o man**

THE BLOOD TRANSFUSION EXPERIENCE

KEY NEGATIVE IMPLICATIONS OF BLOOD TRANSFUSION

Time-consuming

The time and full days required to undergo the blood transfusions..

.

Limiting planning

The regular intervals and cyclical life puts limits on the patients lives, activities and planning.

Fixating / obligating

The necessity of the blood transfusions in frequent intervals is perceived as a limitation of their freedom.

Iron accumulation consequences

Receiving haemaglobin also means receiving iron, which accumulates in the body and organs producing a number of risks and consequences.

Side-effects of iron chelation medicine

As a bi-effect of the blood transfusions, many patients are administered iron chelation medicine. This produces a number of side-effects (especially exjade) as well as a need for taking supplement for other minerals, e.g. zinc.

Potentially progressing disease

A few patients have the idea that receiving blood transfusions slows down their own production of mature blood cells, potentially worsening their condition and progressing negatively.

THE BLOOD TRANSFUSION EXPERIENCE
QUOTES

“I perceive the blood transfusions as something there is keeping me alive. I am not terrified or upset about them. I am happy and grateful.

- MDS Patient #6, Man, 80, 2 years with MDS

“I received my first blood transfusion three-quarters of a year after I was diagnosed with MDS. I was scared to death; I was so afraid. Now it is just a part of my life. I show up and get them without thinking further.”

- MDS Patient #1, Woman, 68, 20 years with MDS

“You can easily feel it in your body. Your thigh muscles are not sore anymore and your cheeks becomes more red. It is lovely. Sometimes I get sort of high because of the new energy.”

- MDS Patient #4, Woman, 72, 4 years with MDS

“It improves my quality of live to receive the blood transfusions. They enable me to do something the subsequent weeks.”

- MDS Patient #8, Woman, 80, 1 year with MDS

DECREASING BLOOD TRANSUFION DEPENDENCY

What it would mean for patient to decrease blood transfusion dependency

FRAMING QUOTE OF THE SECTION

“It would give me some more peace and quiet. I would be able to take longer vacation. It is always burdensome to go to the hospital and you get reminded of how sick you are. Being dependent on someone taking care of you is a burden, so of course I would like not to go if it was possible. But given that I am sick, then I am really happy somebody does take care of me.”

MDS-patient #6, Man, 80, 2 years with MDS

FRAMING QUOTE OF THE SECTION

> **”I want to be free just like everyone else. It is always annoying to have something that you cannot control. In terms of the blood transfusions I do not have a free choice.”**

MDS-patient #1, Woman, 68, 20 years with MDS

RELEVANCE OF MEDICAL LAUNCH
DECREASING BLOOD TRANSFUSION DEPENDENCY

The idea and impact of decreasing blood transfusion dependency was discussed directly with the patients, through two scenarios: one decreasing time spent pr. transfusions and one increasing the intervals, i.e. time between the transfusions. We will discuss each scenario in more detail, but overall we should note the following on decreasing BT dependency:

- First of, blood transfusions are an ingrained part of the MDS treatment, and **many have difficulties imagining a life without blood transfusions.** The transfusions keep them alive and able to lead a close to normal life, so the idea should be presented with some caution, as patients are likely to be concerned with reducing transfusions.
- Overall, however, **decreasing dependency is positively received among the patients and there is no substantial threshold for relevance – any improvement is welcomed.**
- Nonetheless, scenario B, increasing intervals and time between transfusion, alleviates significantly more of the negative impacts of MDS and the blood transfusions discussed in the former sections, whereas scenario A, reducing time spent pr. transfusion, only speaks to reducing the iron accumulation risk as the time itself is not seen as an issue.

THE BLOOD TRANSFUSION EXPERIENCE

HESITANCE TO IMAGINE A LIFE WITHOUT BLOOD TRANSF.

“I would feel let down [if no longer getting blood transfusion]. It is something that I like and keeps me alive. If it stopped, I would worry about not getting it anymore. Scared and worried of how it [MDS] might progress. Being unprotected.”

MDS Patient #6, 80 y/o man
2-3 weeks BT interval, MDS for 2 years

“You would lay flat down and die without blood transfusions. It is simple as that. There isn’t any other medicine to our group.”

MDS Patient #7, 72 y/o woman
4-week BT intervals

SCENARIO A

Decrease time spent

What would it mean for patients if time spent on a blood transfusion decreased (number of units)?

SCENARIO B

Decrease frequency

What would it mean for patients if the number of blood transfusions were decreased

SCENARIO A

Decrease time spent

What would it mean for patients if time spent on a blood transfusion decreased (number of units)?

Decreasing time spent would not present a significant positive impact for the patient

There is consensus among the patients that the time gained would not make any large benefits – although still welcomed. This is mainly due to the fact that the actual transfusion only present a fraction of the time spent and patients already ascribe the full day to the transfusions. Many patients also highlight that since they are retired, the questions of time is not that important to them.

Lowering the number of units creates hopes for a minimized iron accumulation risk and side-effects

Limiting the number of blood units is perceived very positive in terms of iron accumulation. The hopes are that reducing time and units will also limit the risk of iron accumulation – and the need for iron chelating medicine. There is also some worry, that they will not reach the haemoglobin level needed to function.

Overall this scenario does not present any major benefits, however any improvement is of course welcome. For this scenario arguments should focus on the potential decrease of iron accumulation.

BLOOD TRANSFUSION DEEP DIVE
QUOTES ON SCENARIO A

“I don’t think it would mean much. Because the time consuming is not receiving the blood itself – it is about 45 minutes pr. unit. But it is everything else that needs to fall in place. So there isn’t much benefit in saving a bag.”

MDS Patient #2, Man, 71 y/o, 15 years with MDS

”It would not mean a thing for me to leave an hour earlier. But if I could take a pill instead of going to transfusion it would make a lot of difference”

MDS Patient #7, Woman, 72 y/o, 4 years with MDS

”I prefer as few units as possible since the blood contains a great amount of iron. The iron is unwelcoming because it can ravage kidneys, liver and other internal organs.”

MDS Patient #1, Woman, 68, 20 years with MDS

“I have retired, so I do not have any obligations beside my friendships. For me one hour less or more does not have an impact.”

MDS Patient #6, Man, 80 y/o, 2 years with MDS

SCENARIO B

Decrease frequency

What would it mean for patients if the number of blood transfusions were decreased

Increasing the intervals would have a significant positive impact on life quality by increasing freedom

Increasing the intervals would first and foremost **alleviate some of the feelings of fixation and obligation** that is associated to blood transfusions and free up time for more long-term planning without having to be near one's hospital – decreasing overall hospital dependency. **Especially the possibility to travel is highlighted as a significant improvement on quality of life.**

Feeling less like a patient

Going to fewer hospital visits would also imply **fewer reminders of being ill and feeling like a patient**. On the other hand, one should also be **careful not to leave patients with a feeling of abandonment**, no longer being in the hands of the HCP's, with only few other interactions.

Further, increasing intervals are perceived to be the result of maintaining an acceptable haemoglobin level for longer, **alleviating the fatigue and enabling patients to feel well for longer and be less impacted by the limitations set by their MDS.**

Minimized iron accumulation risk and side-effects

Both scenarios are expected to have **positive effects on iron accumulation**, reducing the risk and need for treatments.

BLOOD TRANSFUSION DEEP DIVE
QUOTES ON SCENARIO B

“It would be great if I only needed blood transfusion once every month instead of once every second week – just the fact that I could then travel for 2 full weeks or even 3! That is something you really dream of.”

- MDS patient #2, 71, 15 year with MDS

”It would also mean that you didn’t receive that much iron, so maybe you could skip the iron chelating medicine. That would be wonderful. It has so many side-effects!”

- MDS patient #2, 71, 15 year with MDS

“I would be happy to come in less often. That would give me more peace and quietness in my everyday life.”

- MDS Patient #6, Man, 80, 2 years with MDS

“It would be great if I only needed blood transfusions once every month. That would give me more freedom.”

- MDS Patient #1, Woman, 68, 20 years with MDS

DECREASING BLOOD TRANSFUSION DEPENDENCY
MAIN PATIENT DRIVERS & BARRIERS

DRIVERS	BARRIERS
Increase planning horizon with fewer blocked days; possibly regaining some of the lost social life.	Possibly feeling “left to themselves” and less “cared for”, with limited treatment and HCP interactions.
Feeling less fixated (and more free)	Lacking the social element and sense of belonging to the staff.
Giving increased possibilities for travelling.	Decreasing opportunities to discuss their illness.
Reducing the risk of iron accumulation; and this reducing the side-effects of the iron chelation medicine.	Removing the positive feeling after the transfusions; quick response and improvement.
Feeling less as a patient with reduced hospital visits and longer periods on “normal” haemoglobin levels.	Patients with a long history with blood transfusion may need convincing before agreeing to drop a “life-saving” treatment.
Supporting the body’s own maturing of red-blood cells; thus (perceived) slowing the negative disease progress.	
(Perceived) Possibility to maintain a higher haemoglobin level; and living on “normal” levels for longer periods and thus decreasing the negative impacts of anaemia.	

DECREASING BLOOD TRANSFUSION DEPENDENCY
QUOTES ON DECREASING BT DEPENDENCY

”It is annoying going to the hospital because you get reminded of how sick you are.”

- MDS Patient #2, Man, 80, 2 years with MDS

”It would be nice not having to go, because that would also mean I felt better. On the other hand, then it doesn’t mean that much to me, because at the moment I do not have that much else to do.”

- MDS Patient #5, Woman, 73, 6 years with MDS

“It is very frustrating to be dependent on other people taking care of you.”

- MDS Patient #8, Woman, 80, 1 year with MDS

“Sometimes when I come home after a blood transfusion, I wonder how the day passed away. Then I have spent 8 hours at the hospital after all. You just need to keep your head up.”

- MDS Patient #4, Man, 73, 3 years with MDS

APPENDIX

YOUR DEDICATED TEAM AT IPSOS

SIGGA-DORA HALLDORSDOTTIR
Senior Project Manager
SiggaDora.Hall@ipsos.com
+45 29 89 08 11

STEFAN PAPADAKIS
Insight Consultant
Ipsos UU // Healthcare
stefan.papadakis@ipsos.com
+45 40 13 14 86

SOFIE ODGAARD
Research Assistant
Ipsos UU
sofie.odgaard@ipsos.com
+45 20 97 69 95

About Ipsos

Ipsos is the third largest market research company in the world, present in 90 markets and employing more than 18,000 people.

Our research professionals, analysts and scientists have built unique multi-specialist capabilities that provide powerful insights into the actions, opinions and motivations of citizens, consumers, patients, customers or employees. Our 75 business solutions are based on primary data coming from our surveys, social media monitoring, and qualitative or observational techniques.

“Game Changers” – our tagline – summarises our ambition to help our 5,000 clients to navigate more easily our deeply changing world.

Founded in France in 1975, Ipsos is listed on the Euronext Paris since July 1st, 1999. The company is part of the SBF 120 and the Mid-60 index and is eligible for the Deferred Settlement Service (SRD).

ISIN code FR0000073298, Reuters ISOS.PA, Bloomberg IPS:FP
www.ipsos.com

Game Changers

In our world of rapid change, the need for reliable information to make confident decisions has never been greater.

At Ipsos we believe our clients need more than a data supplier, they need a partner who can produce accurate and relevant information and turn it into actionable truth.

This is why our passionately curious experts not only provide the most precise measurement, but shape it to provide True Understanding of Society, Markets and People.

To do this we use the best of science, technology
and know-how and apply the principles of security, simplicity, speed and substance to everything we do.

So that our clients can act faster, smarter and bolder.
Ultimately, success comes down to a simple truth:
You act better when you are sure.

THANK YOU.