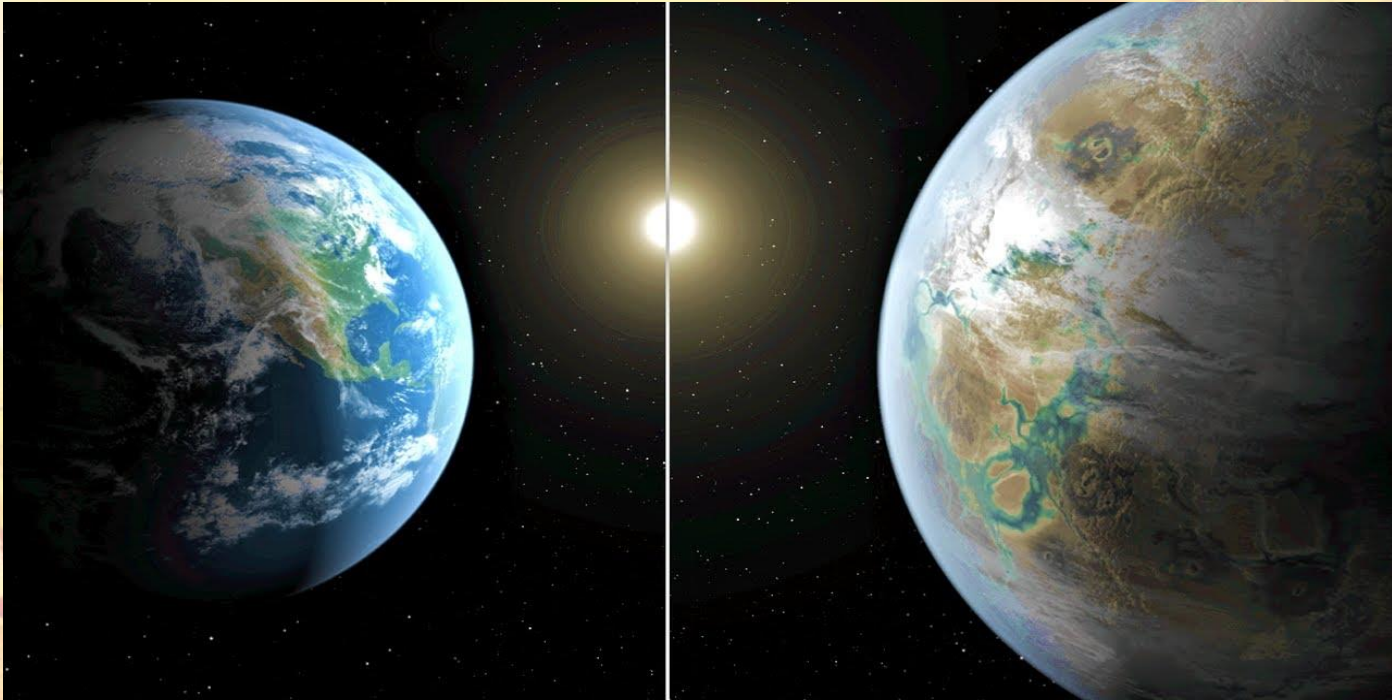


Psychosocial Aspects of Living with Chronic Diseases such as AA/MDS/PNH

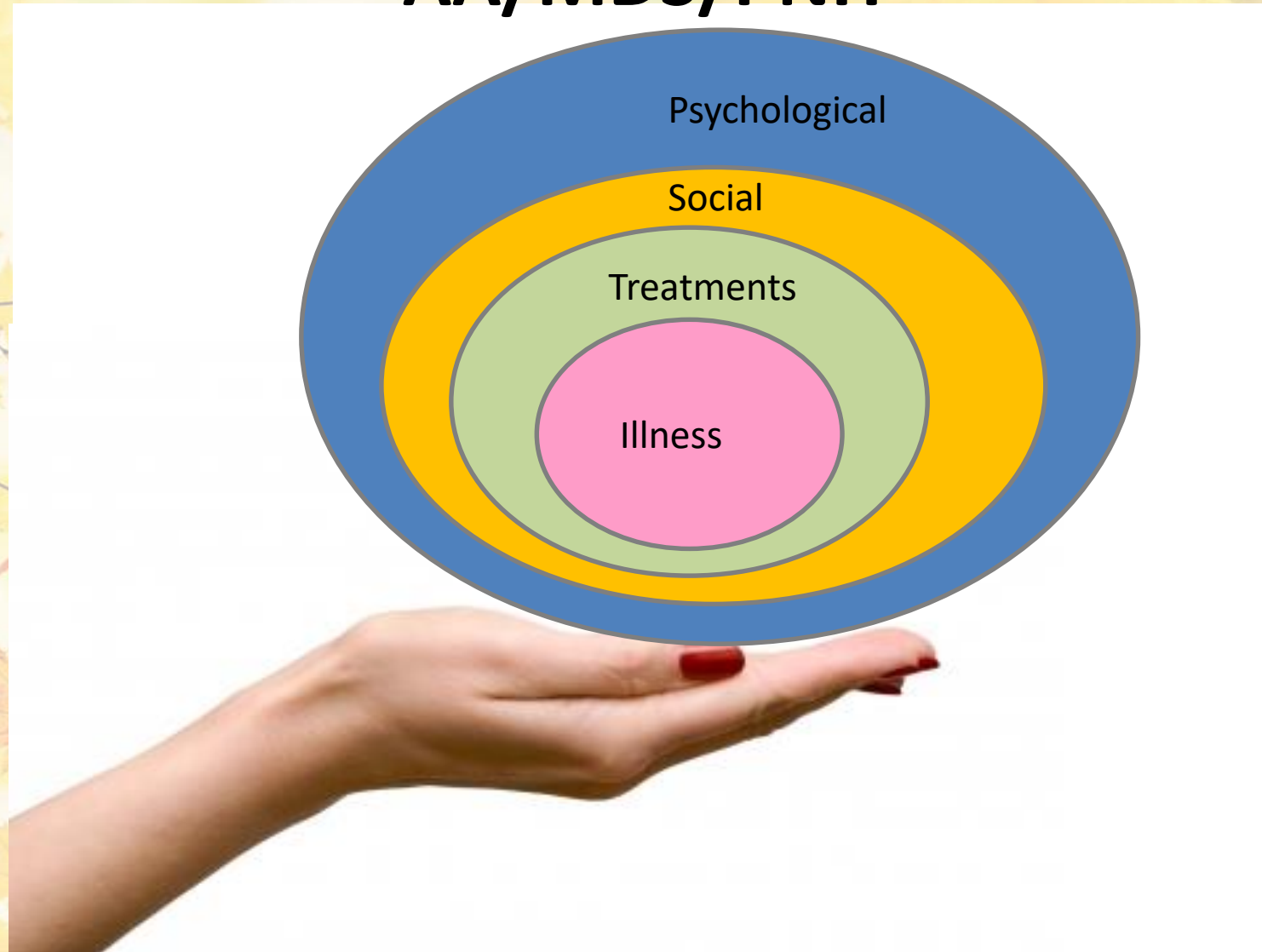
Dr Marie-Eve Gagnon, Psy.D., L.Psych.

October 15th, 2016

Facing a chronic illness



Particular challenges related to AA/MDS/PNH



Difficult symptoms: Fatigue

Most important symptom that affects quality of life [1,2].



- Physical weakness
- Lethargy
- Decreased mental alertness
- Poor concentration^[3]

Other difficult symptoms

- Infection
- Bleeding
- Pain



Managing the illness

- Time consuming
- Hospitalisation
- Side effects
- Costs



Social repercussions

- Changes in who you meet throughout your day
- Relationship dynamics can change
- Communicating with others about the disease can be challenging
- Enrichment of certain relationships



The background of the slide is a soft-focus photograph of autumn foliage. In the foreground, several maple leaves are visible, some in sharp focus showing vibrant red and orange hues, while others are blurred into a bokeh of yellow and orange. The overall lighting is bright and warm, creating a serene and seasonal atmosphere.

Psychological repercussions

Adapting to changes

- Grief
- Frustrations
- Sadness



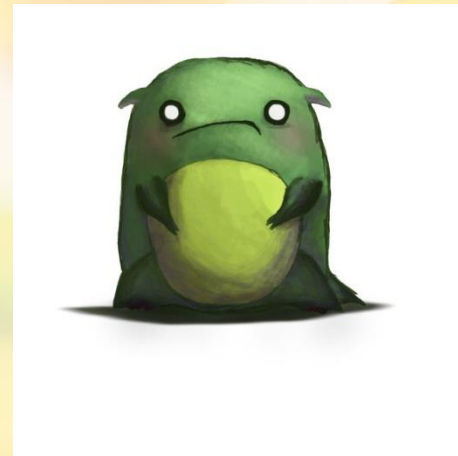
Depression

- Focusing on the darker side of life
- Hopelessness, helplessness and worthlessness
- Isolation
- Loss of interest
- Difficulty sleeping
- Fatigue



Depression

- Focusing on the darker side of life
- Feelings of hopelessness, helplessness and worthlessness
- Isolation
- Loss of interest
- Difficulty sleeping
- Fatigue



Facing uncertainty

- Complexity of illness
- Lack of salient symptoms
- Incongruence between expectations and experience



Anxiety

- Worry
- Ruminative thoughts
- Hypervigilance
- Feeling of dread
- Physical manifestations
- Difficulty sleeping
- Panic attacks
- Irritability
- Difficulty concentrating
- Avoidance

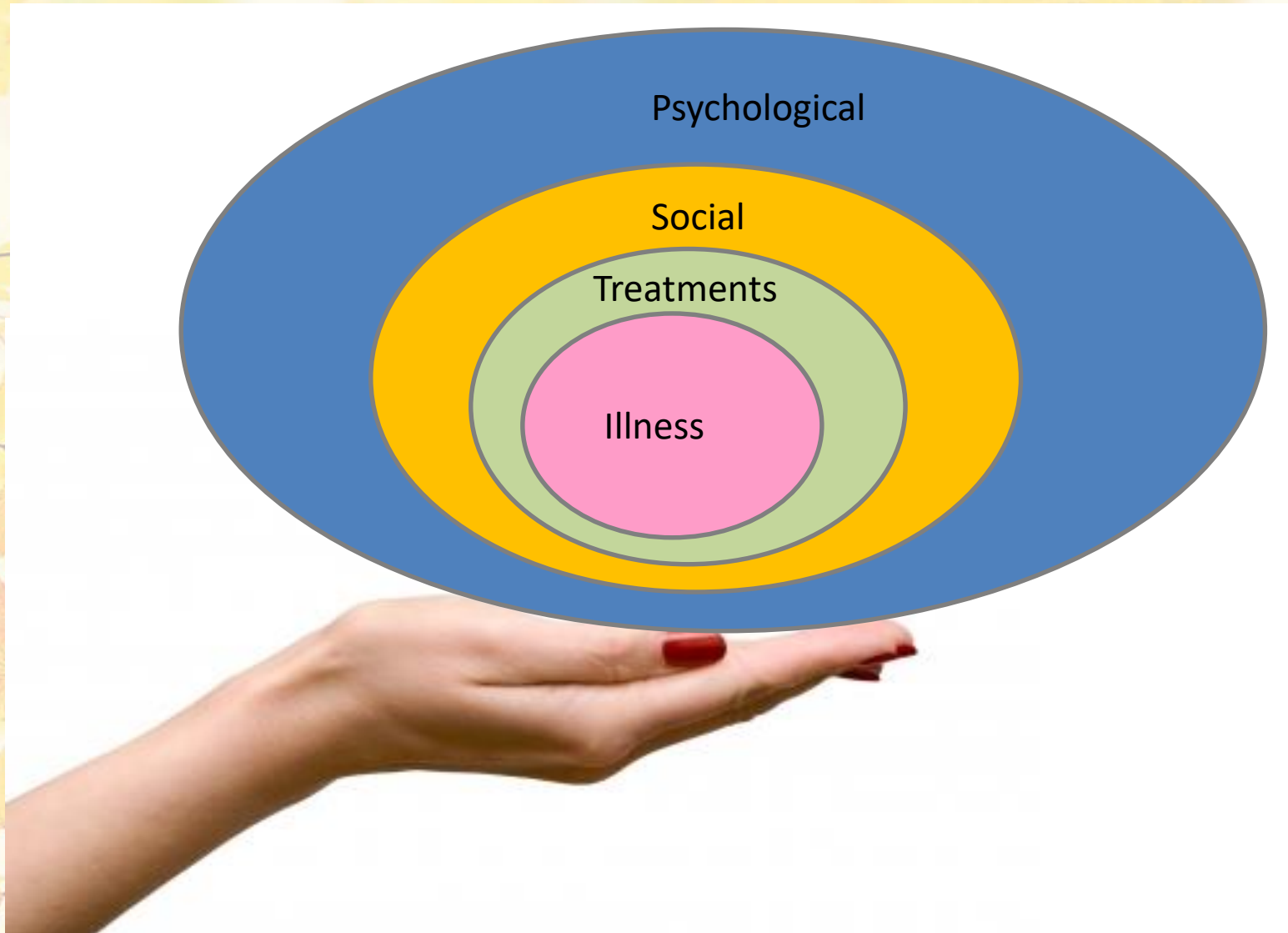


Anxiety

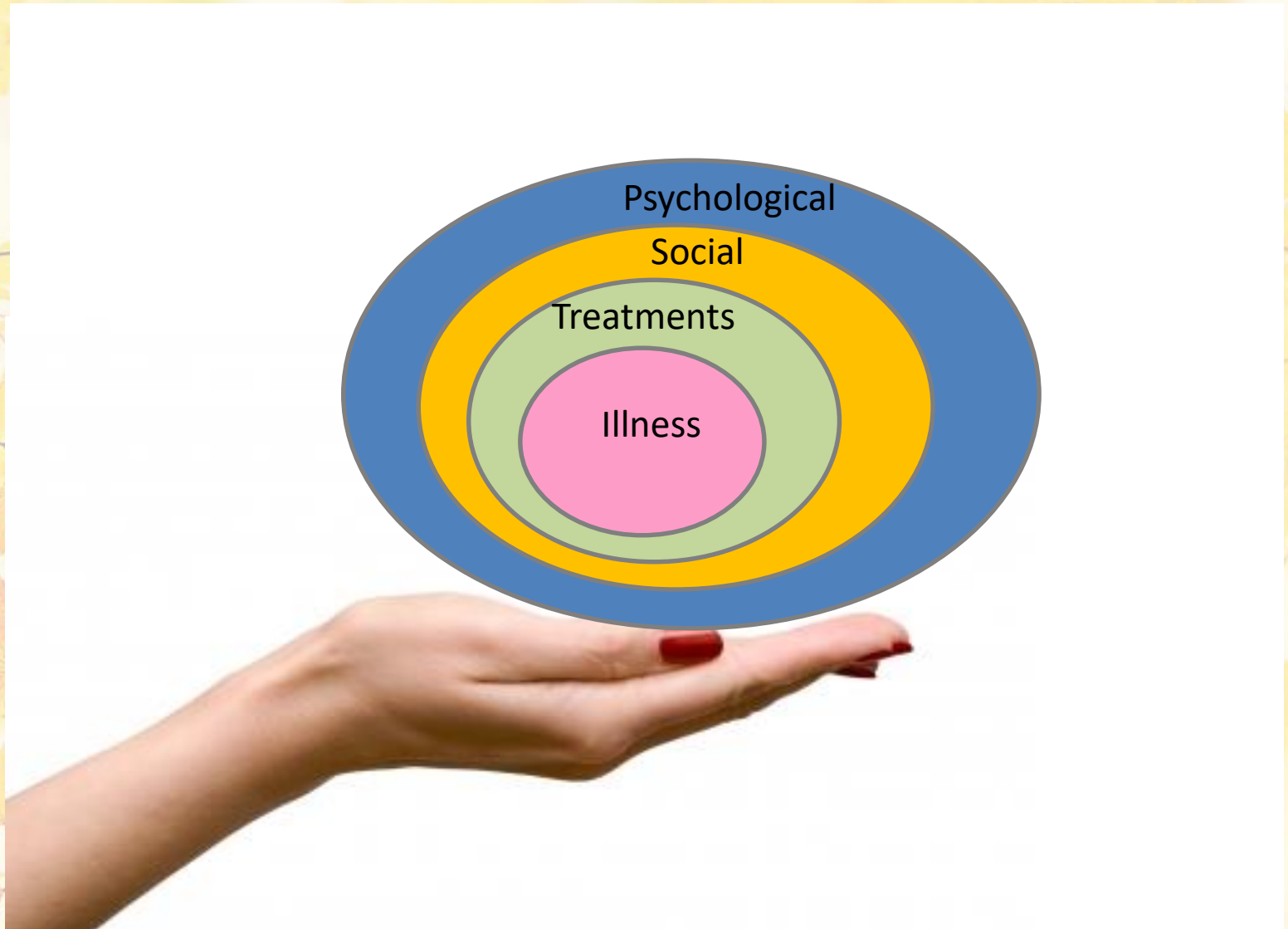
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How to find well-being and happiness with these challenges?

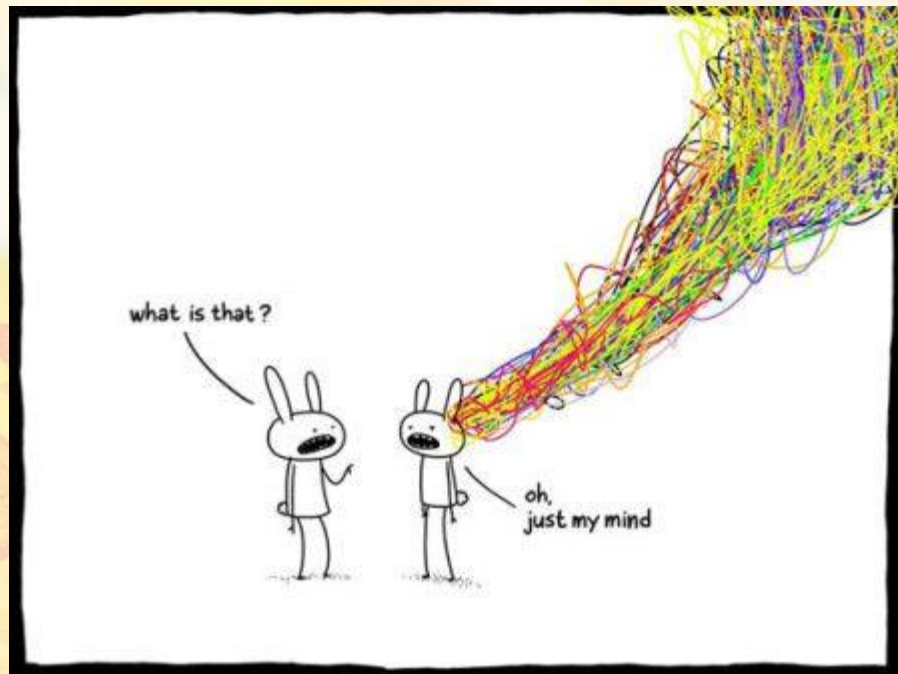


How to find well-being and happiness with these challenges?



A helpful mind

- Noticing the thoughts and patterns
- Are these making sense?
- Are these helpful?



A helpful mind: a few practical tools

- Present moment
- Understanding the illness
- Letting go the 'small stuff'



A helpful mind: a few practical tools

- Fun/ humour
- Social support
- Professional support



A meaningful life

- When you have a limited amount of energy, it becomes even more important to wisely choose where you invest it.
- To you, what makes the difference between **surviving** and **living**?

A meaningful life

“Those who have a 'why' to live, can bear with almost any 'how'.” -- Viktor Frankl

EX: Do not sleep during the next night!



Hope

- The many sides of hope
- Hope in minutes, hope in moments



Acceptance

- Different definitions
- Not 'giving in', or a passive surrendering or being necessarily happy about the changes
- It's recognising the actuality of things as they are in the present
- Choosing where you invest your energy



References

- [1] Steensma, D.P. et al. (2007). Common troublesome symptoms and their impact on quality of life in patients with myelodysplastic syndromes (MDS): Results of a large internet-based survey. *Leukemia Research*, (32), 691-698.
- [2] Escalante, C.P. et al. (2015). Fatigue, Quality of Life and Related Symptoms: Patient Reported Outcomes in Myelodysplastic Syndrome, Aplastic Anemia and Paroxysmal Nocturnal Hemoglobinuria. *Blood*, (26:4456)
- [3] Jansen, AJ et al. (2003). Quality of life measurement in patients with transfusion-dependent myelodysplastic syndromes. *British Journal of Haematology*, (121), 270-274.