



Perceptions of caregivers and healthcare providers about therapies after pediatric allogeneic stem cell transplantation: Barriers and facilitators for medication adherence.

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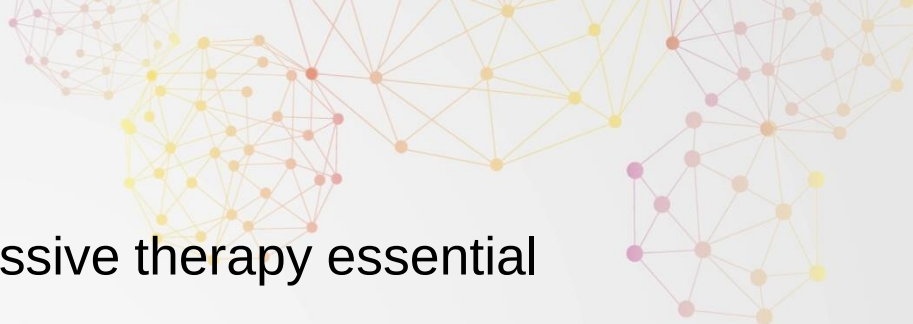


Marseille, the 28th March 2017



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- After allogeneic SCT: Immunosuppressive therapy essential
- Medication adherence in children and adolescents: Suboptimal (52-73%^{1,2})
- Important role of caregivers in pediatrics
- Explanatory Model of Behaviors³ :

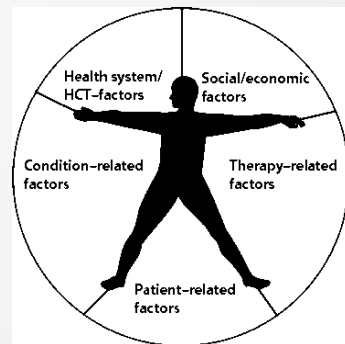
Perceptions : Form the basis for individuals' feelings and reasonings

- Relate needs and expectations about the care system
- Perceptions of caregivers Vs. Perceptions of healthcare providers



Exploring caregivers and healthcare professionals' perceptions

- Semi-structured interviews by a pharmacist
 - **Caregivers** of pediatric outpatient with IS*, and no relapse or complication
 - **Healthcare providers** : medical and paramedical
- Interview Guides⁴
 - The transplantation (Allogeneic SCT)
 - Post-transplantation therapies
 - Perceptions of the healthcare system
 - The caregiver's experience
- Audiotaped, transcribed & manually **analyzed by inductive approach**⁵:
Identified categories & subcategories with respect to the verbatim redundancy



*IS: immunosuppressive therapy

15 caregivers & 21 healthcare providers

Caregivers : 12 mothers, 2 fathers & 1 couple

- Patients' mean age : 6 years
- Pathology: 7 malignant and 8 non-malignant
- Mean number of medications after hospital discharge : 8
- Mean delay between allo-SCT and interview: 99 days (57-177 days)
- Mean duration for an interview : 15 minutes (7-39 min)

Healthcare providers : 7 medical & 14 paramedical

- Mean experience > 6 years in the hospital (except resident)
- Mean duration for an interview : 11 minutes (6-21 min)

Results - Perceptions

The ten first days
(at home), very
complicated...
Time to get back
on track!

**The family, siblings
and entourage**

**Adaptation
Disturbance**

The older sister is
having a little trouble
at this moment (...)
maybe because we're
a bit stuck at home

He is going
very well
today and I
will never
thank them
enough for it

Acknowledgements

**The healthcare
system**

There are
somethings which
should be explained
a little bit more in
advance

It is
reassuring
to know in
advance !

Information

**The allogeneic
SCT**

Ambivalence

This system is
quite heavy, but at
least after the
transplantation he's
healed

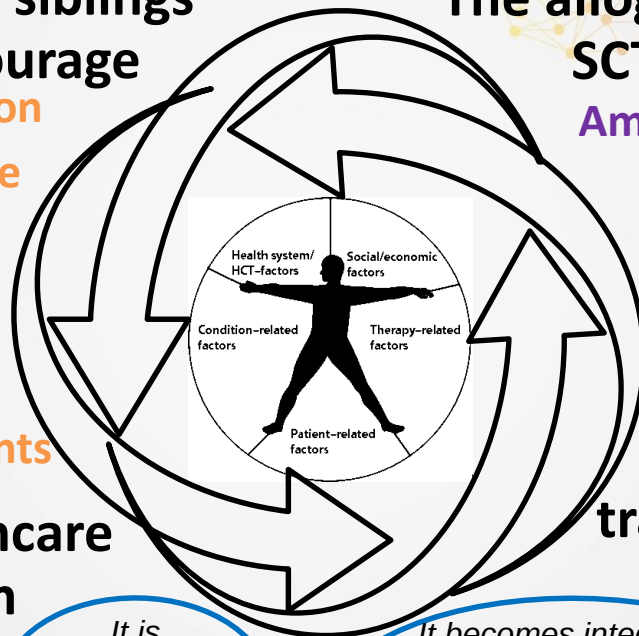
The parents are
happy and in the
same time they are
worried (...) I would
say... it's ambivalent!

**The post-
transplantation
therapies**

It becomes integrated
into the daily routine.
Like preparing
breakfast, they
prepare a syringe

Organization

We set
phone
reminders,
especially
in the
morning
because
sometimes
everybody
sleeps



Results - Factors of Medication Adherence

Facilitators :

- Recognizing the benefits of medication
- Integrating medications into family daily routine
- Garnering support from parents and healthcare providers
- Receiving practical information and explanations from providers
- **Support from the entourage**
- **Term nature of the therapy**

Barriers :

- Bad flavor of syrups (cyclosporin)
- Large number of medications
- Constraints of manipulations
- Sudden transitions of care
- Lack of information coordination between professionals
- **Long term nature of the therapy**

In the adherence which can facilitate is to say that it is not for life, that at some point it will come to an end

Caregivers
Healthcare providers
Caregivers & healthcare providers

Discussion - Needs from the Care System

Focus: “The family, siblings and entourage”

- Need to consider the whole family entity, not just the parent-child dyad

How to communicate information ?

- Concretization : Hospitalization, home medication manipulation
- Coordination : Harmonization between professionals
- Anticipation : Particularly during the transition of care

Conclusion & Perspective

- Perceptions of those responsible for pediatric patients' care: both their caregivers and healthcare professionals
- **Close perceptions**, in the context of pediatric allogeneic SCT
- **Better understanding of adherence behavior:**
 - Identification of facilitators and barriers for medication adherence
- **Specific caregiver's needs** concerning the care system
 - Communication modalities



Contributions to the improvement of care

Thank you for your attention



No conflict of interest

- ¹ Phipps S, DeCuir-Whalley S. Adherence issues in pediatric bone marrow transplantation. *J Pediatr Psychol*. 1990; 15: 459-475.
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- ³ Nascimento-Schulze CM, Fontes Garcia Y, Costa Arruda D. Health paradigms, social representations of health and illness and their central nucleus. *Papers on Social Representations*. 1995; 4: 187-98.
- ⁴ Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007; 19: 349-357.
- ⁵ Thomas DR. A General Inductive Approach for Analyzing Qualitative Evaluation Data. *American Journal of Evaluation*. 2006; 27: 237-246.