

Assessment of Parents' Learning Needs in Paediatric Oncology

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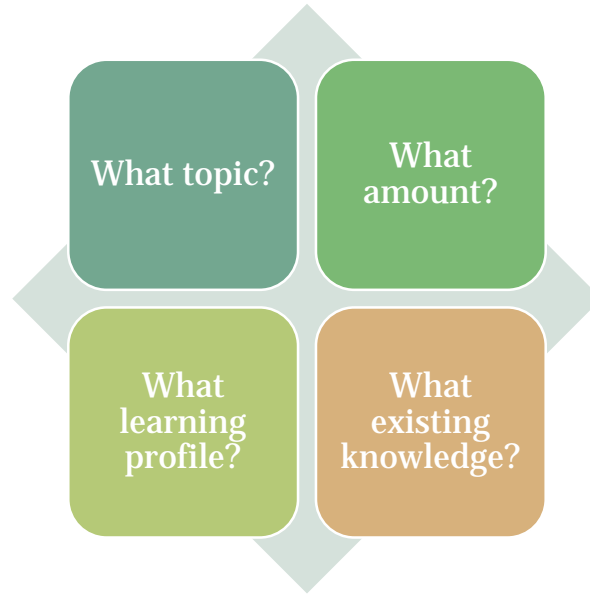
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ASSESSMENT OF LEARNING NEEDS



WHY EDUCATE PARENTS?

And why is this complicated?



BENEFITS OF PARENTAL INFORMATION

- Right to receive information
- Self-care
- Comprehensibility and control
- Informed decision-making
- Imperative for the cooperation (from the HCPs perspective)
- Less psychosocial suffering



CONSEQUENCES OF GOOD AND BAD INFORMATION WORK

Feeling acknowledged as a person of significance

- Feeling safe and secure in spite of uncertainty
- Having one's hopes supported
- Getting relief from sharing other families' experiences

Feeling like an unwelcome guest

- Feeling abandoned at important milestones
- Feeling forced to nag for information
- Feeling burdened by the obligation to inform others



COMPLEX AND COMPLICATED

- Hard to grasp the disease
 - Large body of knowledge to be acquired
 - Difficult words
- Hard to adapt to the information
- Hard to get information
- Hard to know what one needs to know
- Hard to get a suitable amount of information



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WHY ASSESS THE LEARNING NEEDS?



BECAUSE PARENTS DIFFER

KISS – keep it simple and stupid
(Gibson et al., 2018).

If you could start by telling us a little more. Begin with talking about what happens with the blood cells during the treatment and so. If you are interested in science, you rather soon understand the effects of these drugs. But you could describe that from a medical perspective, too.

(Ringnér et al., 2013)



ARE THE NEEDS ASSESSED?

I work really closely with the consultants, so I can predict what they're going to say in a given situation because I've sat there 90 times while they've done that talk. And it's always the same...

(Gibson et al., 2018)

Well, you take a blood sample called Information in serum, and then you check the result.

(Ringnér et al., 2011)



BENEFITS OF ASSESSING NEEDS

1. Aimed information
2. Effective
3. Heterogeneous group with different previous knowledge
4. Probably greater parental satisfaction



WHEN



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WAYS OF ASSESSING



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WHAT SHOULD AN IDEAL ASSESSMENT INCLUDE?



Topic?



Modality and
pacing?



Understanding?



Amount?



Satisfaction?



FOUR APPROACHES

Simple tools

What
information?

How much
information?

Existing
knowledge and
understanding?



SIMPLE TOOLS

- Asking
- Bedside notepad



PATIENT/PARENT INFORMATION AND INVOLVEMENT ASSESSMENT TOOL

Which sentence best describes the **decision-making role** that you want?

When possible,

- 1) I want to leave all decisions about my child's care to the care team.
- 2) I want the care team to make the decisions about my child's care. But I want the care team to seriously listen to my views.
- 3) I want to share in making the decisions about my child's care with the care team.
- 4) I want to make the decisions about my child's care. But I will seriously listen to the care team's advice.
- 5) I want to make all decisions about my child's care.

Compared to what I want, my decision-making role is:

Too small *Just right* *Too big*

Which sentence best describes **how much information** you want about your child's care?

When possible,

- a) I want the simplest information you can give me.
- b) I want more than the simplest information. But keep it in everyday terms.
- c) I want more than the simplest information. I also want help to understand things in depth.
- d) I want as much in-depth and detailed information as you can give to me.

Compared to what I want, the information I get is:

Too little *Just right* *Too much*



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THE KeSO AND RkSO

I expect knowledge about...	Fully agree	Partly agree	Partly disagree	Fully disagree	N/A
1. Symptoms related to my child's disease and treatment	1	2	3	4	0
2. When we should contact the hospital if the symptoms get worse	1	2	3	4	0
3. Examinations that will be performed on my child	1	2	3	4	0
4. How to prepare my child for examinations	1	2	3	4	0



CHECKLISTS

Table 2. Primary Topic Checklist.

Topic	Learner
Meeting with physician team for diagnosis and treatment plan	
Meeting with social worker to screen for immediate psychosocial needs	
Diagnosis (parents know how to convey this in an emergency)	
When to call for help	
Who to call for help	
Fever	
Temperature-taking	
Handwashing	
Preventing infection	
Treatment side effects to know before next appointment	
Home medication: Names and purpose	
Home medication: Dose and frequency	
Home medication: Administration	

Rodgers, *J Pediatr Oncol Nurs*, 35(4), 235-46; Haugen, *J Pediatr Oncol Nurs*, 33(6), 405-13

Educational Topic	Rank Order	Mean-Rank Score
Topics for all newly diagnosed pediatric oncology patients (1 = most important; 18 = least important)		
Diagnosis		
Treatment plan		
Fever	1	16.66
Prognosis	2	14.18
Side effects of treatment	3	12.23
Who/how to call (eg, days, nights, weekends)	4	11.43
When/why to call treatment team	5	11.32
Clinical trials	6	10.98
Managing medications	7	10.70
Central line care	8	9.91
Care of the child at home	9	9.34
Supportive care	10	8.98
Health care team (key members)	11	8.89
Preventing infection	12	7.73
Blood counts	12	7.73
Follow-up appointments	14	7.20
Fertility preservation	15	
Psychosocial		

Home medication: Prescriptions are filled at the pharmacy place to

REPRESENTATIONAL APPROACH (I)

Identity

Cause

Timeline

Consequences

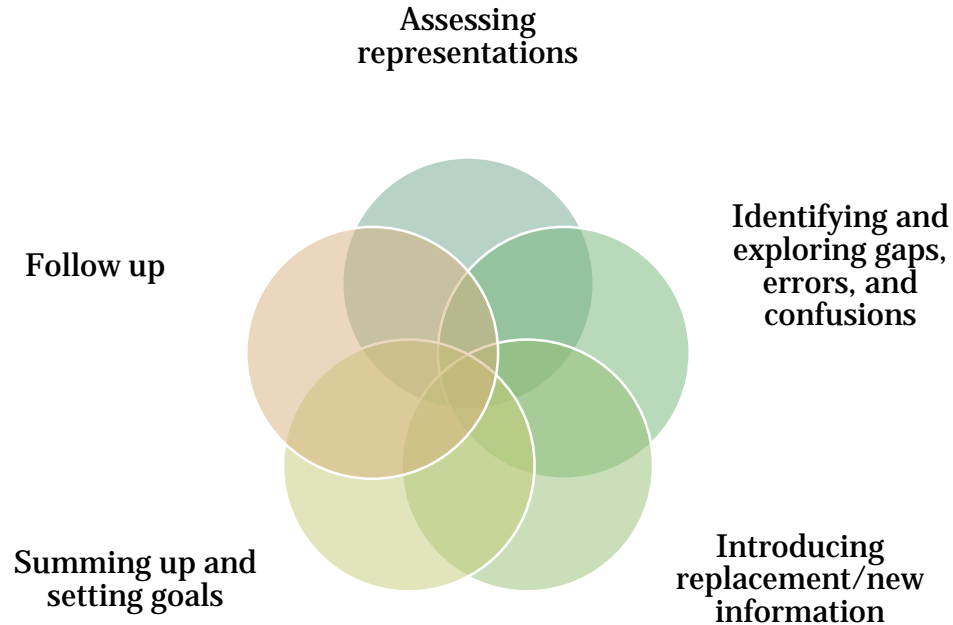
Cure or
control

Emotional



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REPRESENTATIONAL APPROACH (II)



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A photograph of a rocket launch. The rocket is white with a black band and a red三菱 (Mitsubishi) logo. It is surrounded by a massive, billowing plume of white smoke and orange fire. The launch is taking place on a hillside. In the background, there are red and white support structures. The sky is a clear, pale blue.

JUST LAUNCH IT!

References available at
<https://bit.ly/kyotoref>