

EVALUATING THE NEEDS CHILDREN WITH CANCER HAVE, BY USING THE INTERACTIVE TOOL “SISOM”

PILOT STUDY: THE RESULTS



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Introduction



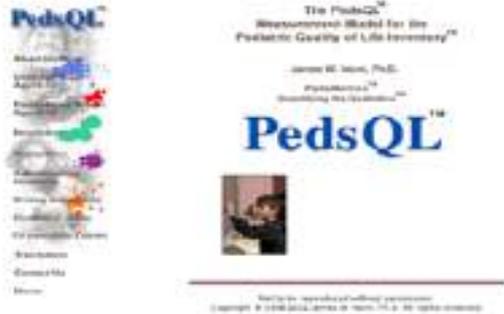
- The continuous progress at the treatment of cancer during the latest decades, has resulted in a great number of children who are cured.
- The use of new tools, results to the valid evaluation of needs and problems those children report to have.



- Ruland C. M., Hamilton G. A., Schjødt – Osmo B. The Complexity of Symptoms and Problems Experienced in Children with Cancer: A Review of the Literature, *J Pain Symptom Manage* 37:403 – 418, 2009
- Ruland C. M., Starren J., Vatne T. M. Participatory design with children in the development of a support system for patient - centered care in pediatric oncology, *Journal of Biomedical Informatics* 41:624–635, 2008
- Vatne T. M., Slaughter L., Ruland C. M. How Children With Cancer Communicate and Think About Symptoms, *Journal of Pediatric Oncology Nursing* 27(1): 24 – 32, 2010

Evaluation tools

- **PedsQL 3.0 Cancer Module**



- **M.S.A.S.**



- **Common Criteria Toxicity**

- **Peds CHOICE**

- **Pain Squad**

- **Sisom**





SISOM:

- ✓ Interactive, evaluation tool
- ✓ Children aged 6 – 13 years old
- ✓ Friendly to children
- ✓ Promotes communication between children and nurses
- ✓ Effective evaluation of symptoms and problems



- Ruland C. M., Hamilton G. A., Schjødt – Osmo B. The Complexity of Symptoms and Problems Experienced in Children with Cancer: A Review of the Literature, *J Pain Symptom Manage* 37:403 – 418, 2009
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Aim

To evaluate the affect an interactive tool (Sisom) has on understanding and evaluating the needs and problems children with cancer face daily

Hypothesis

Sisom's use ensures the effective evaluation of symptoms children with cancer have, compared to an interview





Method

- 10 month study (February 2014 – November 2014)
- Children (n=30) aged 6 – 13 ετών (M.O. 8,9 έτη) hospitalized to the pediatric oncology departments of the hospitals “Agia Sofia” and “P. & A. Kyriakou”
- Preconditions:
 - ✓ Children aged 6 – 13 years old
 - ✓ Children should have been diagnosed the last year
 - ✓ Children and parents should speak Greek or English fluently
 - ✓ They should not suffer a final stage disease

Method



- At first, the researcher interviewed children about their disease and the problems and needs they have
- Then, Sisom was presented and children were asked to use it
- After finishing with Sisom, children were given a small “present” as a reward for accepting to take part to the study
- Whole meeting time: 30 min

Method – Data analysis

- Qualitative research
- Grounded Theory



Results (a)

- ❑ Children that could take part to the study: $n = 42$
- ❑ Children who finally took part to the study: $n = 30$
- ❑ Denial:
 - Parents: 9
 - Children: 3



Results (b)

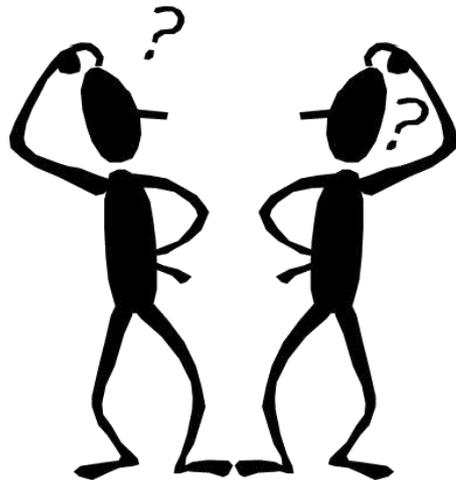


Childhood's cancer is taboo!!!

- ✓ Parents refuse to inform children about the diagnosis
- ✓ They avoid even the “**cancer**” word



- What do we do to fix that?
- What is our role as nurses?
- Are there any forbidden words allowed in our field?



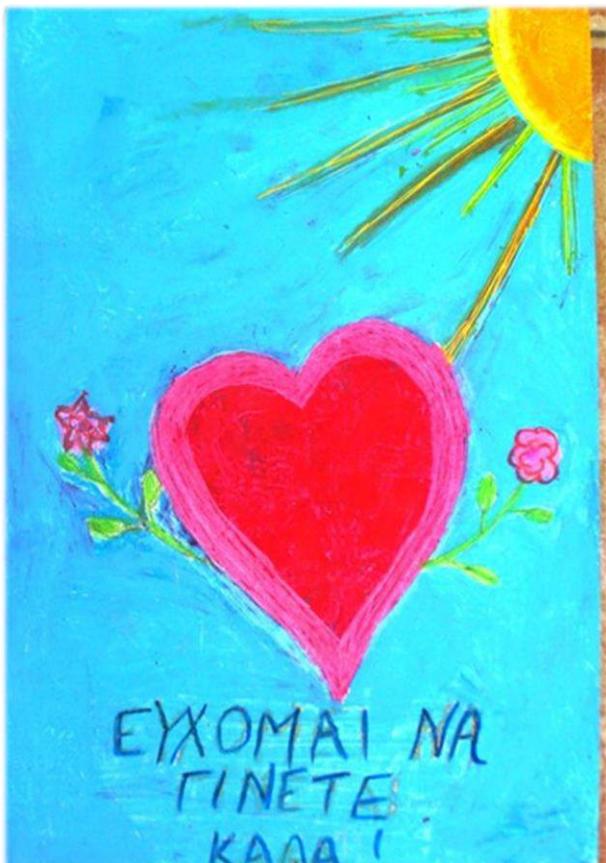
Results (c)



SEX	N (%)
BOY	18 (60%)
GIRL	12 (40%)

DIAGNOSIS	
	N (%)
LEUCEMIA	15 (50%)
LEMFOMA	3 (10%)
SOLID TUMOR	12 (26,7%)

Results (d)



CHILDREN WHO VISITED ISLAND	
ISLANDS' NOUMBER	CHILDREN
5	22
4	5
3	1
2	1
1	1

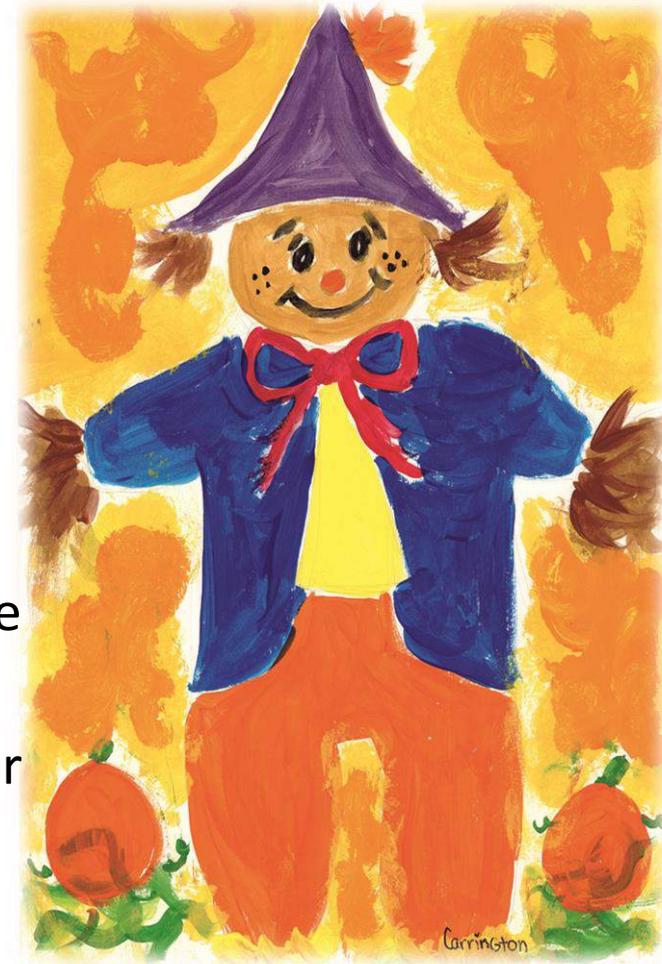
Results (e)



ISLANDS CHILDREN DID NOT VISIT	
ISLAND	CHILDREN
THINGS ONEMIGHT BE AFRAID OF	7
HOSPITAL	4
ABOUT MANAGING THINGS	3
THOUGHTS AND FEELINGS	3
MY BODY	2

Results (f)

- Children reflect themselves to the hero of Sisom
- By using Sisom, more children admitted that they miss at least one thing from their daily life (n=25), in contrast to the interview (n=4)
- About pain, only 4 children gave a clear answer and 12 children hesitated. By using Sisom, >90% referred at least one cause of pain



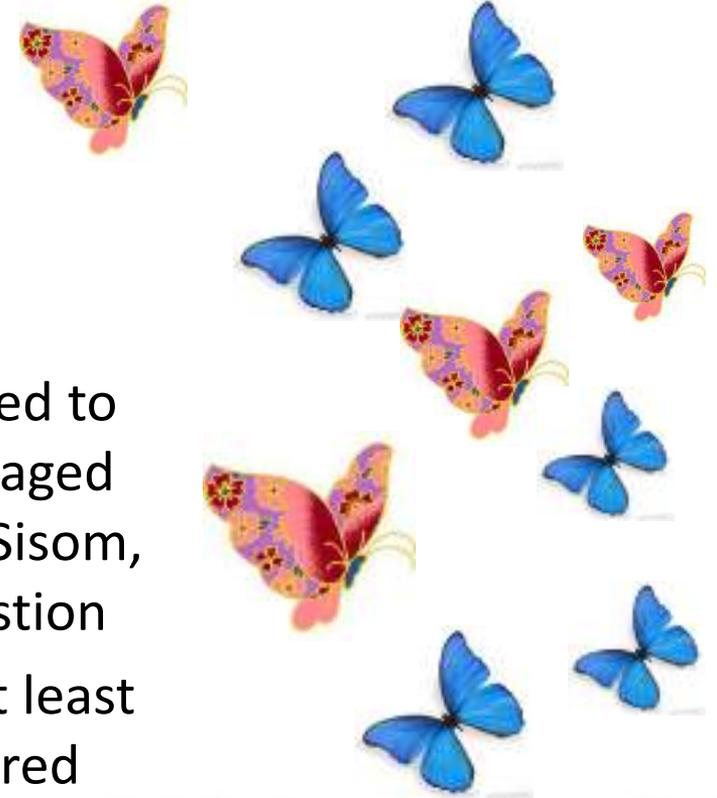
Results (g)

- During the interview, all children answered positively to the question «Do you feel sad while in hospital?»
 - ➔ 28 avoided any clarification
 - ➔ Parents' reactions affect them
- By using Sisom, even the older children who appear to be more “brave”, are afraid about their health and emotionally they get affected by their family. They also feel guilts.
- During the interview, 8 children admitted to have nightmares, while by using Sisom 14 children said “yes” to that question



Results (h)

- During the interview, only 3 children admitted to feel “different” from other children of their aged and only 1 child gave clarification. By using Sisom, 17 children answered positively to that question
- With the interview, 11 children expressed at least one fear, while by using Sisom, >90% answered positively to the questions they were asked



Results (i)

Sisom as an expression tool for the child with Down syndrom

- 1 child had Down syndrom
- During the interview, he appeared to be defensive, denied to answer at the questions and demanded either for Sisom or for me to leave
- During Sisom he appeared to be really excited – He visited all islands
- The father was pleased too – Asked whether the tool was used on daily basis



Restrictions

- Relatively small sample
- Did not have the ability to check children during the different phases and for a long time

Conclusions

- The use of an interactive tool (Sisom) is a reliable and effective way to record the symptoms children with cancer have, compared to an interview
- During the interview, children get affected by:
 - Family
 - Child's character



INTERVIEW:

- ✓ Family affects children
- ✓ Sociable parents – with no secrets:
 - Comfort during the interview
 - Give information about how they feel
 - Clarify their answers
- ✓ Parents less sociable:
 - Less comfort during the interview
 - Did not clarify when they gave answers



SISOM:

- ✓ Children are excited for using a “game” while hospitalized
- ✓ Most children visited all islands
- ✓ Even the children who did not visit every island, gave more information on their situation than with the interview



...because kids can't
fight cancer alone.

THANK YOU