

Sisom: Interactive communication support to help children with cancer communicate their illness experiences and improve consultations

Cornelia M. Ruland, RN, PhD^{1,2}

¹Center for Shared Decision Making and Collaborative Care, Oslo University Hospital,

²Faculty of Medicine, University of Oslo, Norway

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Children with Cancer

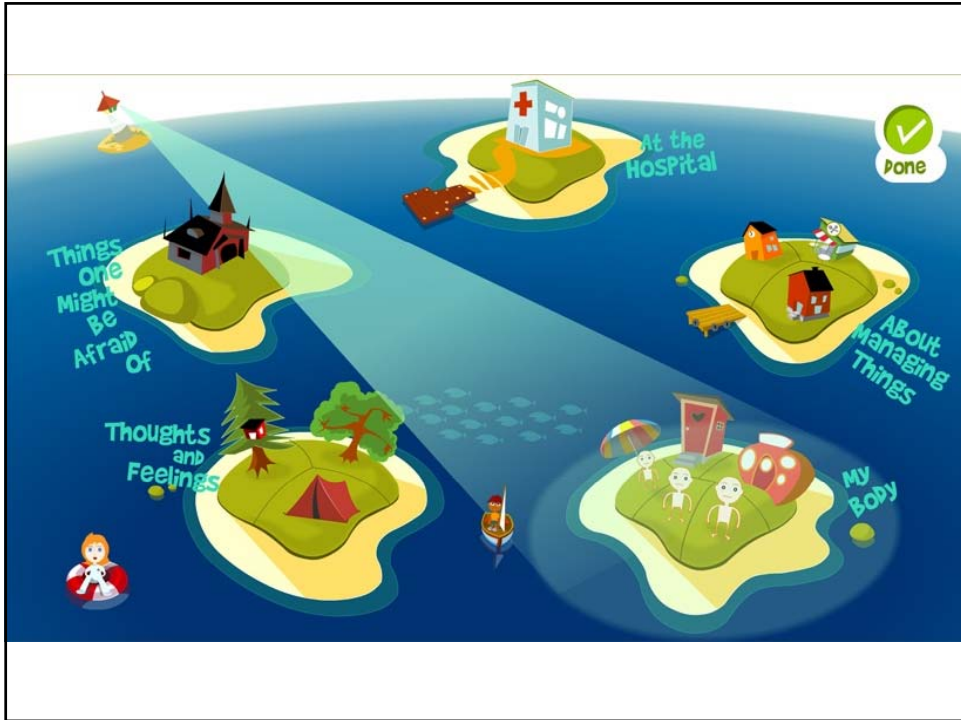
- Particularly vulnerable, lack life experience and skills to cope with illness
- Children perceive the world differently
- Limited verbal skills
- Little participation in consultations
- Symptoms and problems at risk for being under-diagnosed and treated

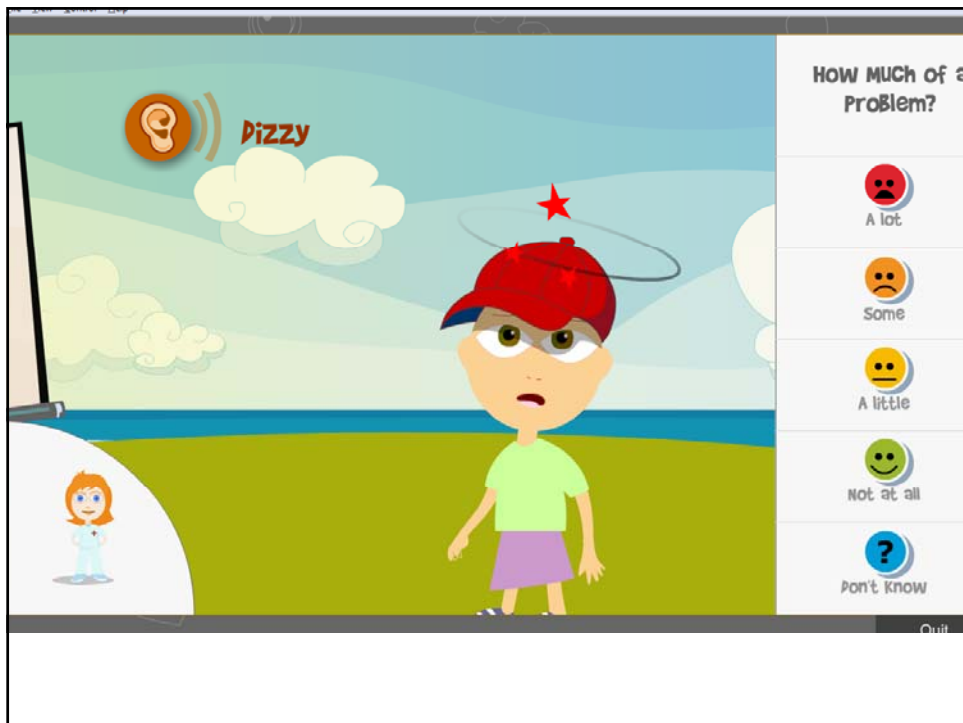
SiSom

An interactive communication tool to:

- Help children with cancer communicate their symptoms and problems – give them a “voice”
- Help care providers to better understand and help the child





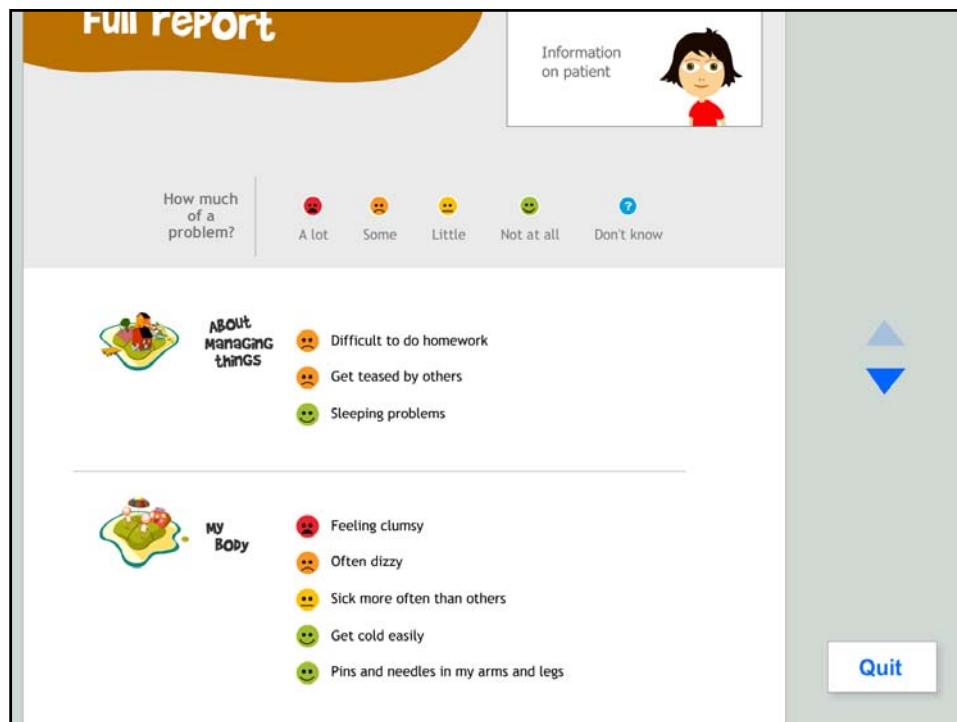




Sleeping Problems

how much of a problem?

- A lot
- Some
- Little
- Not at all
- Don't know



Research studies to test Sisom

Does Sisom improve patient care and communication in pediatric consultations in terms of:

- Number of symptoms/problems picked up and addressed
- Child participation in consultations
- Clinicians' communication?

Study Design

- Control group:
 - Usual care
- Sisom group:
 - Children used Sisom prior to consultation
 - Report given to clinicians, child and parents in the consultation

Study methods

Videotapes of 26 consultations

10 in the control group

16 in the Sisom group

Analysis by two coders

Participants:

- Six boys and seven girls age 8-12 undergoing cancer treatment, 1-3 consultations each.
- Fifteen physicians, 1-5 consultations each.

Significant group differences

26 consultations	Control group N= 10 Mean	SiSom group N= 16 Mean
Symptoms addressed	4.3	7.9
Child participated	3.7	6.4
Child addressed	3.9	6.3
Identified problems	1.7	4.5

Results Active Use

	Control group N= 17 Mean	SiSom group N= 9 Mean	Significance	
			t	p
Symptoms addressed	4.6	10.0	3.2	.004
Child participated	3.6	8.7	2.8	.002
Child addressed	3.4	9.1	3.9	.001
Identified as problem	2.1	5.8	3.0	.01
Acknowledge	1.9	4.3	2.5	.02
Probe	3.0	5.8	2.1	.04
Explain	1.3	3.3	2.4	.02
Empathy	.94	3.3	3.1	.005

Results repeated with children with heart disease

	Sisom group N= 42 Mean	Control group N= 42 Mean	p
Symptoms addressed	10.7	5.9	< .001
Child participated	8.0	4.3	< .05
Child addressed	6.7	2.1	< .001
Information provided	25.2	15.6	< .05

No increase in consultation time

Discussion

- What you can put into words is easier to handle ...
- Learn new things from the child
- More "honest" answers – children often don't want their parents to worry
- Taps into children's skills: express themselves through avatars, pictures and stories
- Sisom identifies what the child needs help with but also a sense of normality: what I still can do – the positive
- Easier to inform others

Discussion

On the doctors' and nurses' side:

- Communication changed significantly
- Sisom can effectively improve patient-centered care, even without much provider training
- Consultation time did *not* increase
- More prepared, more efficient
- Shared understanding and report with the child- child as partner

Cont'd

- Sisom easily adopted and used in various settings, e.g. clinical practice, home, others who interact with a child
- Applicable to many different illnesses
 - Children with heart disease
 - Diabetes module under development
 - Many others

Our goal

- Given the positive results: offer Sisom to as many children around the world as possible
- Parents and health care professionals can download Sisom from the CommuniCare Foundation website for use
- As a charitable foundation CommuniCare seeks to collaborate with all who wish to help us spread Sisom and promote further research, development and translation etc.

Sisom Download

www.communicarefoundation.org

...follow link

Sisom for children with Cancer: English, Spanish and Norwegian languages

Contact

- If interested to collaborate or if you have ideas or would like to help us improve or make Sisom available to more children, please come and speak with me or contact me:

cornelia.ruland@rr-research.no

Please see also two more Sisom presentations from American /Canadian colleagues in Nursing session 1 tomorrow

- Christina Baggot: Abstract # O 020 – 11.40
- Argerie Tsimicalis: Abstract # O 019 – 11.20

Thank you for your attention!