



Evaluation of Sisom: A computer-based animated tool to elicit symptoms and psychosocial concerns from children with cancer



Christina Baggott^{a,*}, Jennifer Baird^a, Pamela Hinds^{b,c}, Cornelia M. Ruland^d,
Christine Miaskowski^a

^a School of Nursing, University of California, 2 Koret Way, Box 0610, San Francisco, CA 94143, USA

^b Children's National Health System, 111 Michigan Ave., N.W., Washington, D.C., USA

^c The George Washington University, USA

^d Center for Shared Decision Making and Collaborative Care Research, Oslo University Hospital, Forskningsvn. 2b, N-0027 Oslo, Norway

A B S T R A C T

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Purpose: In pediatric oncology, clear communication regarding symptom occurrence between clinicians and children is essential in order to provide safe and effective care. Mobile technology provides a means to enhance the standard clinician–patient interview, particularly among children, who are well versed in the use of technology. To help children identify and voice their concerns in the health care setting, researchers created Sisom, an animated computer tool for children and young people with serious and chronic illnesses. The purposes of this study of 100 dyads of patients 7–12 years of age and their parents were to: compare participants' reports of symptom occurrence using Sisom to a standard symptom checklist and determine the time requirements, ease of use, and perceived usefulness of the Sisom tool by children with cancer and their parents.

Methods: Child and parent participants completed both Sisom and the Memorial Symptom Assessment Scale. Symptoms on the two tools were compared and 20 items were similar to allow for comparisons.

Results: Children reported a significantly higher number of these 20 symptoms using Sisom as compared to the MSAS (i.e., 6.8 versus 4.9 symptoms, $p < 0.001$). A similar pattern was noted for parental proxy reports (i.e., 8.7 versus 5.7 symptoms, $p < 0.001$). Sisom was completed in less than 30 min, with high ratings of ease of use and perceived usefulness from parent participants.

Conclusions: Sisom provides a systematic and engaging method to elicit symptom reports from children for use in clinical care and research.

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Introduction

Children receiving cancer treatment experience numerous disease- and treatment-related symptoms (Baggott et al., 2010; Poder et al., 2010; Williams et al., 2012). Effective symptom management

depends on patients' or parents' ability to report symptoms and clinicians' ability to pose specific queries and provide appropriate interventions. However, clinicians' ability to accurately detect symptoms and psychosocial concerns is low, even among adult patients (Fromme et al., 2004; Sonn et al., 2013). Clinicians encounter additional challenges when they assess symptoms in children. Factors that may impede children's ability to report symptoms include the child's developmental level and verbal skills, as well as the communication styles of clinicians and parents (Coyne, 2008). In fact, children's participation in clinic encounters is quite low. In one study (van Dulmen, 1998), children's comments accounted for only 4% of the encounter, because most communication was directed towards parents.

The use of technology holds promise as a means to augment the standard clinician–patient interview, particularly among children, who are described as “digital natives” (Prensky, 2001). To help

Abbreviations: Sisom, A play on the Norwegian phrase “Si det som det er”, or “Say it like it is”; MSAS, Memorial Symptom Assessment Scale; REDCap, Research Electronic Data Capture; SD, Standard Deviation.

* Corresponding author. Present address: Stanford University, Cancer Clinical Trials Office, 800 Welch Road, MC 5757, Palo Alto, CA 94304, USA. Tel.: +1 650 497 7659.

E-mail addresses: baggott@stanford.edu, christina.baggott@ucsf.edu (C. Baggott), Jennifer.Baird@childrens.harvard.edu (J. Baird), PSHinds@childrensnational.org (P. Hinds), Cornelia.Ruland@rr-research.no (C.M. Ruland), chris.miaskowski@nursing.ucsf.edu (C. Miaskowski).

Table 1
Symptom occurrence reports from children and parents.

Item description	Child responses		Parent responses	
	Occurrence (% yes)	Number of responses	Occurrence (% yes)	Number of responses
<i>Sisom physical symptoms</i>				
Eating is difficult	26	100	36	97
Want to eat often	61	97	73	97
Drinking is difficult	16	100	31	97
Things taste or smell different	41	98	64	94
Often thirsty	52	97	63	97
Trouble sleeping	40	99	49	97
Need help with washing and getting dressed	31	100	47	97
To do things by myself is difficult	37	98	46	97
Get tired quickly	56	99	76	97
Can't do anything for very long	36	93	57	90
Tired a lot	55	95	76	92
Feel sick	42	93	49	94
Feel cold	49	93	48	93
Hot or sweaty	46	97	44	91
Throwing up	28	98	31	95
Dizzy	28	96	29	97
Tingling in arms or legs	19	92	22	93
Feeling clumsy	33	94	45	94
Trouble breathing	17	92	18	89
Stuffy nose	45	96	33	93
Coughing	41	96	40	94
Shaky hands	33	98	21	94
Trouble walking or running	41	98	66	93
Trouble hearing	14	89	16	80
Eye problems	29	97	35	91
Feel the heart beating fast	32	96	36	94
Lots of hair on my body	25	97	24	97
Got no hair	46	97	46	93
Gotten fatter	25	99	33	96
Gotten skinnier	34	94	35	96
Can't hold it when I have to pee	28	96	26	98
Have to go to the bathroom all the time	26	99	32	98
Diarrhea	21	94	36	98
Pooping hurts	31	97	33	94
Peeing hurts	10	97	10	93
<i>Sisom psychosocial concerns</i>				
Shots hurt ^a	76	98	92	98
Anesthesia feels awful ^a	44	91	63	92
Difficult to take medicine ^a	48	96	65	93
Checking blood pressure hurts ^a	21	98	35	98
Taking off a band-aid hurts ^a	56	100	85	97
Central line dressing changes hurt ^a	54	91	84	86
Getting an IV hurts ^a	78	95	89	93
Getting a tube feels awful ^a	71	56	73	51
Taking out stiches hurts ^a	58	52	63	48
Blood draws hurt ^a	39	97	78	97
Treatment is uncomfortable ^a	65	94	93	91
Relaxing is difficult	22	100	45	97
Can't follow when others talk	30	95	41	86
Concentrating is hard	52	96	82	90
Don't learn as much as the others	39	91	52	83
Forget things	51	89	67	85
Reading and writing is difficult	29	97	58	93
Tired of talking and nagging	37	97	67	95
Feel lonely	46	98	71	93
Act younger than I am	31	96	39	94
Angry	49	96	76	96
Sad	52	98	76	95
Embarrassed	34	99	59	95
Feel stupid	18	97	34	92
Nothing is fun anymore	36	97	46	95
Believe others are upset because I'm ill	52	94	46	95
Think that it's my fault that I'm sick	26	93	24	83
Cannot be with my friends as much as before	66	93	74	96
Feel different from other children	62	100	83	93
Miss my family and friends	62	97	73	96
Difficult to get answers to things I'm wondering about	42	94	59	95
Telling people how I feel is difficult	54	95	82	96
Would like to be by myself more	35	99	43	96
Miss home	55	93	62	94
Would like to make my own choices more often	56	98	85	97
Don't know what I want	50	96	72	95

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