

This is the authors final draft post-refereeing article published in Journal of pediatric oncology nursing

Vatne TA, Slaughter L, Ruland CM  
Journal of pediatric oncology nursing 2010, 27(1)  
Url: <http://jpo.sagepub.com/cgi/reprint/27/1/24>

## **How Children Communicate and Think about Symptoms**

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Acknowledgement:

This study was supported with partial funding from the Norwegian Research Council

grant #: 175389/V50

## Abstract

**Background:** For clinicians to effectively help children with their illness and symptoms, it is important to communicate with them in a language they can understand.

**Methods:** This study investigates how well children with cancer and healthy children understood 44 symptoms terms; their thoughts about these symptoms in terms of causes, consequences and cures; and what other terms the children used to express these symptoms. It also explores if there were differences in understanding and thoughts about symptoms between children who had the experience of cancer and those who had not. Six children with cancer and eight healthy children participated in semi-structured interviews.

**Results:** Children demonstrated a good understanding of symptom terms, yet were not always able to explain the symptoms. They had a rich vocabulary to talk about symptoms, but did not use childish terms. Children with cancer had a more varied vocabulary for symptoms, but they did not use more medical terms. This study contributes to knowledge about children's understanding of symptoms that can be helpful to clinicians when communicating with children about their illness.

**Key words:** Childhood cancer, symptoms, patient-provider communication, vocabulary, understanding and beliefs

**Short bios for authors:**

Torun Marie Vatne received her Master of Science Degree at the Psychological Institute, University of Oslo in 2003. She worked as a clinical psychologist at a paediatric cancer ward 2003-2004 at Rikshospitalet University Hospital and became a full time Ph.D. student at the Centre for Shared Decision making and Nursing research in 2005. Her main interests are patient-provider communication and paediatric psychology.

Dr. Slaughter has recently joined as a researcher the Interventional Centre at Rikshospitalet University Hospital in Oslo, Norway and the Dept. of Computer and Information Science, Norwegian University of Science and Technology (NTNU) in Trondheim, Norway. Her contributions to this paper were done during her three years as a researcher at the Centre for Shared Decision Making and Nursing Research. Dr. Slaughter's interests are in health informatics and the design of health-related ICT for both health personnel and patients.

Dr. Ruland is the Director of the Center for Shared Decision Making and Nursing Research Rikshospitalet University Hospital, a Professor at the University of Oslo in Norway and a clinical nurse specialist in pediatric nursing. A recipient of a number of research grants, she is the head of a larger program at the Center that is devoted to novel technologies to improve shared decision making and patient-provider communication in health care. . She is the primary PhD advisor for Torun Vatne.

## INTRODUCTION

Over the last decades, there has been a remarkable progress in the treatment and prognosis of childhood cancer, yet for children to be diagnosed with this illness remains a difficult experience. Children with cancer suffer from multiple physical, emotional, psychosocial and behavioural symptoms (Patenaude & Last, 2001). However, there are large variations in how children experience their symptoms and problems, including self-awareness and distress (Collins et al., 2000; Hockenberry, 2004), which makes it difficult for clinicians to automatically anticipate what children are experiencing and consequently, what care is in their best interest.

For clinicians to provide best possible care, eliciting and communicating with children about symptoms and problems from the child's perspective is crucial. Through communication with the children, clinicians can gain insights into children's symptom experiences, reactions and illness-related beliefs (Woodgate et al., 2003; Targosz et al., 2001), which allows them to prevent or alleviate symptom distress, improve emotional well-being and satisfaction with care (Matley 1997 as ref. in Veldtman et al., 2000).

Communication with children about their symptoms is difficult due to less developed verbal and cognitive skills, especially if the symptom terms used are not known to the child (Scolnik et al., 2003), or if clinicians and children ascribe different meanings to a symptom term without being aware of it (Ley, 1988; Hadlow & Pitts, 1991). Furthermore, the verbal contributions of children during medical consultations have been found to be small or even absent (Tates & Meeuwesen, 2001). Particularly for younger children it is difficult in a "traditional" conversation to talk about difficult topics. Children are therefore, at a particular risk that their symptoms and problems remain under-diagnosed and treated. Thus children could benefit from support tools that help them communicate their symptoms and problems to their care providers.

To help children communicate their symptoms and illness experiences from their perspective, our research team developed SiSom<sup>1</sup>, an interactive, computer-assisted communication tool to help children age 7-12 with cancer report their symptoms in a child-friendly, age-adjusted manner. SiSom provides the children with "a voice" and helps care providers to better communicate and address children's

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<sup>1</sup> SiSom is the Norwegian acronym for **Si** det **Som** det er, meaning: "Tell it as it is", or **Selvrapportering Innen Symptomer Og Mestring**, meaning: Self-reporting on Symptoms and Management.

symptoms and problems in patient care. The interactivity and graphical and audiovisual functionalities made possible by the computer provides entirely different possibilities than questionnaires to capture children's experiences of symptoms and problems from the child's own perspective, and in a manner adapted to their developmental stage. SiSom uses spoken text, sound, animations and intuitively meaningful metaphors and pictures to express or depict symptoms and problems that even younger children who cannot read can respond to. The development of SiSom and methods the research team used to determine graphical representations and selection of understandable, child-friendly terms used in the system are described in detail elsewhere (Ruland et al., 2008b).

For a system like SiSom to be truly useful, it is important that children can understand the symptom terms it contains. Therefore, the purpose of this study was to evaluate how well children comprehend these symptom terms, their thoughts about symptoms, and to learn what other terms children may use to express symptoms. Another goal was to explore if there were any differences in understanding and thoughts about symptoms between children who had the experience of cancer and those who had not. Semi-structured interviews with six children with cancer and eight healthy children were used to answer the following research questions:

- 1) How do children age 7-12 understand the 44 physical symptom terms used in SiSom?
- 2) What alternative expressions do children use to talk about these symptoms?
- 3) What do children think about symptom causes, consequences and cures?
- 4) What are the differences between healthy children and children with cancer in their understanding, thoughts about causes, consequences and cures, and use of alternative expressions of symptom terms?

An influential model of people's thoughts about an illness is Leventhal's model of illness representation (Leventhal et al, 1980) that was used to guide our research questions. This model states that people think about illness in terms of values on dimensions. These dimensions are: a) identity- what is the name and symptoms associated with the illness? b) Consequences - what will happen as a result of the illness? c) Time and course - how does the illness progress, is it chronic, acute or intermittent? d) Cause - what causes the illness? e) Cure - what will cure the illness?

Studies have found that adults' descriptions of an illness and knowledge about types of illnesses are organized around these dimensions. Leventhal et al's model has

also been said to characterize young children's representations of illness (Goldman et al., 1991) and thus was considered suitable for our study.

### **Previous research**

Children have a less developed vocabulary compared to adults and use different words. In general, earlier studies on children's understandings of symptoms have focused on the words school-aged children use to describe symptoms (Hinds et al., 1999; Stanford et al., 2005; Van Cleve et al., 2004; Champion et al. 1998 as ref in Finley & McGrath, 1998; Harbeck & Peterson, 1992; Robertson, 1993) and body parts (Scolnik et al., 2003). However, two studies have focused particularly on children with cancer and the expressions they use to describe symptoms. Hind and colleagues found that these children use different words to describe fatigue than adults (Hinds et al., 1999). Van Cleve and colleagues who studied pain in children with cancer found that the most frequently used words to characterize pain were "uncomfortable" and "annoying" (Van Cleve et al., 2004).

Other studies have focused on healthy children's language for general pain, sports-related pain and body parts. Stanford and colleagues found that the most frequently used expressions for pain are "hurt", "ouch", and "ow" (Stanford et al., 2005). The term "Pain" is used infrequently and gradually emerges in children's vocabularies with age (Nemeth et al., 2005). Studying children's words for genitals, Scolnik and colleagues concluded that use of the medically correct words may limit communication between children and health personnel; because children may not know the correct words (Scolnik et al., 2003).

While there has been little research on the terms children use to express symptoms, more studies have focused on children's thoughts about an illness. The literature includes research on topics such as illness concepts (Kalish, 1999), illness understanding (Buchanan-Barrow et al., 2003; Bird & Podmore, 1990), illness representation (Goldman et al., 1991; Paterson et al., 1999) and illness perception (Carr, 2001).

A child with cancer lives with the illness every day. Therefore, the symptoms may be considered as "rough spots" in "getting through cancer", or "the symptoms may become the illness" when symptoms are frequent, severe or constantly present (Woodgate & Degner, 2004). Therefore, clinicians need to understand how children think about symptoms because their thoughts may affect how they perceive intensity

(Thastum et al., 2005), and may determine their emotional and behavioural reaction (Nemeth et al., 2005) e.g. whether they search for help (Woodgate et al., 2003).

Research that has focused on children's beliefs and expectations related to symptoms has been scarce. Woodgate and colleagues found that children have definite beliefs and expectations about symptoms that are associated with the experience of suffering, including "short-term pain for long-term gain", "you never get used to them", "they all suck", "it sort of helps" and "they are all the same but they are all different" (Woodgate et al., 2003). Beliefs and expectations contribute cancer symptoms being ignored, unrelieved or uncontrolled. (Woodgate & Degner, 2004) Studying the course of symptoms over time, Woodgate and Degner found that children may experience cancer symptoms as overall feeling states. Furthermore, children's ways of experiencing symptoms go through six transition states during the treatment period named "it's just the flu", "it's more than the flu", "it hits home", "it is nasty", "it is not so bad, it's pretty good", and "it is "dragsville"" (Woodgate & Degner, 2004).

Children also perceive symptoms differently from adults. In the example of fatigue, children emphasized the physical sensation of fatigue and viewed rest and distraction as their primary sources of improving the symptom (Hinds et al., 1999), while adults emphasise alternating and at times merging physical and mental tiredness. Davis and colleagues found that children experience fatigue as three different levels of energy, and manage fatigue through replenishing, conserving, and preserving strategies, dependent on their temperament, lifestyle, environmental factors, and treatment modalities (Davies et al., 2002).

Related to the symptom of pain, the most frequently used strategy found for pain management in children were stressor modification, medication, sleep, hot/cold, and massage (Van Cleve et al., 2004). In another study on hospitalized children's thoughts about pain, children's descriptions of pain were generalized, and the most common coping strategies were "lie down", "wish for it to go away", and "tell my mother and father". (Kortesluoma & Nikkonen, 2006). Cognitive beliefs held by children with arthritis were found to be significantly associated with the prediction of pain (Thastum et al., 2005). A study of pain in young gymnasts found that there were age differences in the number of different types of pain identified by children, their understanding of pain causality, the value of pain, how they distinguished pain from exertion, and their use of pain descriptors. Also, gymnasts expressed that there was

little they could do about chronic pain, yet appreciated that pain could intensify with exercise (Nemeth et al., 2005).

However, children with cancer do not only experience pain and fatigue, but a whole range of symptoms. So far little is known about their understanding of other physical symptoms, the verbal expressions they use, and the meaning they ascribe to symptoms in terms of their thoughts about causes, cures and consequences. The purpose of our study was to contribute to the state of knowledge in this area.

## **METHODS**

### **Symptom Terms used in SiSom**

The symptoms contained in SiSom that were used for evaluation in this study were based on a review of the scientific literature to identify the breadth and depth of physical, psychosocial and behavioural symptoms and problems children with cancer can experience, and the language and concepts they use to express and communicate their symptoms from their own perspective. This literature review is described in detail elsewhere (Ruland et al., 2008a). A total of 219 distinct symptoms or problems were identified from the literature and a preliminary list of symptoms was abstracted for potential inclusion in SiSom. Next, a set of focus groups with clinical specialists (physicians, nurses, psychologists) were conducted who critically reviewed the preliminary symptom list for relevance, comprehensibility, completeness, and level of detail and refined it based on expert opinion. The list was thereafter reviewed by six parents of children with cancer for comprehensibility and completeness of terms who suggested refinements of some terms to make them more child-friendly. The resulting symptom list consisted of 78 symptoms whereof 44 are the physical symptoms that were evaluated in this study. This subset rather than the entire symptom list was used to limit children's response burden when asking them about their understanding of symptoms.

### **Study Participants**

Prior to this study IRB approval was obtained. Included were children diagnosed with cancer and healthy children, age 7 to 12. As the experience of cancer may influence how children express and think about symptoms, both sick and healthy children were included, to be able to compare their understanding, expressions and thoughts about symptoms.

Over a period of six months in 2005, a total of 14 children were interviewed. School staff and hospital staff made initial contact with potential participants and handed out written information about the study. The research group contacted participants by phone after their written approval for being contacted. Informed consent was obtained before the interview and children were informed about the study's purpose. They were told that there were no right or wrong answers, that they were not obliged to answer all questions, and that participation was voluntary.

Seven children with cancer, eight to 12 years of age, were identified by their physician at a University hospital in Oslo from the electronic health record. These children had just finished or were at the end of their treatment for cancer. Four had leukaemia and two soft tissue tumours. The interview of one girl was not included in the analysis because she was not able to go through the interview. Thus six children, two boys and four girls provided data from the cancer group.

The healthy children were recruited from a local school with the help of the school's Principal who distributed letters to parents, asking permission for their child to participate in one of the tasks associated with the development of SiSom. The interviews described here were one of these tasks. To match healthy children to children with cancer on gender and age, a convenience sample of eight school children, four boys and four girls age 9 to 11, were invited to the interview and all consented. Except for ensuring at inclusion that these children did not have any chronic diseases or disabilities, no other medical information was obtained from them.

### **Interviews**

Data were collected with semi-structured interviews related to 44 of 46 physical symptoms contained in SiSom. Two symptoms were excluded because of being too cancer specific ("loose hair" and "the wig itches") with no relevance for healthy children.

The child was told that the purpose of the interview was to find out how children think and talk about symptoms. The child was presented with one symptom at a time in random order. To prevent the interview from becoming too personal in nature, the child was asked to create a fictive person with the same age and sex as him-/herself and in the same life situation, and give him or her a name. The child was asked questions from the fictive child's perspective, and each symptom/bodily was introduced in the following manner: "Anne (the fictive child) has "a head ache....."

The interview guide addressed our research questions according to Leventhal's model of illness representation described earlier (Leventhal et al., 1980) (Table 1).

TABLE 1 (see below)

### **Procedure**

Ten interviews were completed in the children's homes after school, three at the paediatric ward and one at the interviewer's office. Interviews were audio-taped. In two instances with children with cancer, the parents were present during the interview. The parents were asked to give as little input as possible.

The interviews were conducted by the first author, a psychologist experienced in interviewing children with serious illness. The interview time ranged from one to two hours, and included one 15 minutes break. The interview was stopped when finished, or earlier if the child wished. For the majority of children the interview lasted for 1 ½ hours.

### **Data Analysis**

The data material consists of verbatim transcriptions of the audiotapes from the interviews. The transcripts were coded using the software program QSR N-Vivo (Fraser, 1999).

The interviews were first divided into sections, where each section represented one symptom. Next, the transcribed text related to each symptom was read and coded into five mutually exclusive categories: a) understanding of the symptom term, b) alternative expressions for the symptom term, and perceived c) cause, d) cure, and e) consequence of the symptom.

The analysis then proceeded in the following manner: Text related to understanding of the symptom terms was coded into three categories: a) The child answered that it could understand the term and could explain when the symptom may be experienced, b) The child said it could understand the term but could not explain when the symptom might be experienced, and c) The child answered that it did not understand the term. Next, alternative expressions children had suggested for symptom terms were coded into a set of subcategories that emerged (Table 2).

Finally, text related to children's perceived causes, cures and consequences of symptoms were read one by one for all symptoms and coded as into subcategories that emerged as displayed in Table 3. N-Vivo searches were used to count the frequency of answers in each category given by the healthy children and the children with cancer respectively (Table 4).

## **RESULTS**

### **Children's Understanding of Symptom Terms**

Children with cancer answered 72% of all questions about understanding and 63% of all questions about cause, consequences and cures. For healthy children the numbers were 92% and 73% respectively.

Most of the time the children answered that they understood the symptom terms presented to them. Ninety percent of answers from children with cancer and 96% of healthy children's answers were: "Yes I understand". There were four symptom terms understood and explained by all children in this study. These were "Feeling cold", "Am hot and sweaty", "Vomiting", and "Have a nosebleed".

However, the children had more difficulties verifying their understanding by explaining when a symptom may be experienced. In 24,7% of the times when children with cancer answered "Yes I do understand", ( 17,1% for healthy children) they were not able to explain when one might experience the symptom. Inability to explain a symptom was evenly distributed over the symptom terms. "No I do not understand" represented 4% of answers from healthy children and 10 % of answers from children with cancer, related to 20 symptom terms. There were no obvious patterns related to which symptom terms the children did not always understand.

### **Similarities and Differences in Ways Healthy Children and Children with Cancer Express Symptoms**

When asked what the fictive child would say to tell someone else about the symptoms, the children modified or came up with 111 alternative expressions or modifications. Forty-two (62,3%) of these expressions were suggested only by children with cancer, compared to 28 (33%) suggested by healthy children. Only 4,7 % were suggested by children from both groups.

The alternative or modified terms proposed by the children were coded into four categories based on the nature of the term: "Synonyms", "more childlike

expressions”, “More specific expressions”, and “More generalized expressions”. The two last categories were divided into several subcategories as presented in Table 2.

TABLE 2 (see below)

Most of the alternative terms proposed by the children were coded as “More specific expressions”. Only a few were coded as “more childlike”. Children with cancer proposed more synonyms, specified the intensity of a symptom more and came up with a cause more often than the healthy group, that in turn proposed more lay terms. Table 3 presents the number of alternative expressions provided by each group.

TABLE 3 (see below)

### **Similarities and Differences in Ways Healthy Children and Children with Cancer Think About Symptom Causes, Cures and Consequences**

Several sub-categories for the dimensions cause, cure and consequence of symptoms emerged from the analysis (Table 4). Children with cancer answered 72% of the questions about the cause of a symptom, but fewer about a cure (61 %), and even fewer about the consequences (59%). The healthy children answered 82 % of the questions about consequences, fewer about the cause (67%) and least about a cure (66 %).

TABLE 4 (see below)

#### ***Causes of symptoms***

The causes that were most frequently mentioned were “Bodily condition-pathological” accounting for 30,7% of the answers from children with cancer and 37,7% from healthy children. “Internal factors - own actions” accounted for 20,6% of the answers from children with cancer and 30,6% of the answers in healthy children. “Medication” and “Medical procedures” were only mentioned as causes by children with cancer.

### ***Cures for symptoms***

Children with cancer and healthy children presented quite similar thoughts about cures. The cures most frequently mentioned were “Own actions” accounting for 53,3% of the answers from children with cancer and 55,6% from healthy children. “Medication” as a cure was mentioned in 18,6% of the answers from children with cancer and in 21,8% from healthy children. Children with cancer answered that there was no cure for symptoms more frequently than healthy children (15,6% vs. 8,8% of the answers).

### ***Consequences***

The most frequent answer was that there was no consequence of a symptom, followed by “Other symptoms appearing”. (9,2% vs. 4%), Children with cancer provided answers coded as “Remedial action” and “there are no consequences” more frequently than the healthy group (9,2% vs. 4% and 40.1% vs. 29.9% respectively).

## ***DISCUSSION***

Children’s answers in this study indicated a good understanding of the physical symptom terms in SiSom they were asked about. This holds promise that the research team was successful in developing a list of symptom terms children age 7-12 can understand. However, due to a small sample size, generalizations are not possible.

An interesting finding however was that the children in this study were not always able to provide an example of when the symptom might be experienced. There may be different explanations: Lack of ability to explain a symptom may indicate that 1) the term was not really understood by to the child who just wanted to please the interviewer; 2) the child did know what the symptom was, but since it did not have any experience with it, had difficulty explaining it; (3) or asking for an explanation was cognitively too demanding. Whatever the reason, this indicates that clinicians should not take a child’s answer about understanding a symptom as face value, but rather use it as a starting point for communication to be follow-up with more probing questions to get a better insight into the child’s understanding and thoughts.

While the symptom terms used in this study seems to provide children and clinicians with a shared language that is understood by both, this study also found that children use a rich variety of other expressions to describe symptoms, which clinicians should be aware of. Interestingly though, the children did not use many “childish terms”. They mainly used ordinary words and lay expressions. Therefore,

there is no need for clinicians to use a “childish” or metaphorical language when talking with children as it does not necessarily improve communication.

Healthy children proposed more “lay terms” compared to children with cancer. Children with cancer showed a greater variety in the use of terms but they did not use many medical terms. They also tended to specify the intensity of the symptom more than healthy children did, and the alternative terms they proposed tended to be more specific. Children with cancer have usually more experience with symptoms from cancer treatment which may be reflected in the way they talk about them.

The finding that alternative terms tended to be more specific than the original term is different from findings in another study where children’s own descriptions were more generalized (Kortessluoma & Nikkonen, 2006). However, this may be due to the way of questioning during the interviews that could have made the child believe that the interviewer was looking for specifications.

When asked about cures for and consequences of symptoms, children with cancer answered more questions about causes and fewer about consequences, which was the opposite for healthy children. Children with cancer may be more informed and knowledgeable about causes due to the illness, but more reluctant to talk about consequences because they may be viewed as life threatening. Use of cognitive avoidance as a coping strategy has been observed in children with acute and chronic illness (Landolt, Vollrath, Ribl 2002) which may be a possible explanation for this finding.

Pathological bodily conditions were the most frequently mentioned causes of symptoms by both groups, which is reasonable when questioning children about physical symptoms of a disease. Not surprisingly, a symptom being caused by medical procedures or medication (e.g. nausea) was only mentioned by children with cancer.

It is interesting that children from both groups mentioned that a symptom could be a natural body reaction (e.g. being tired), not a sign of an illness. Even children with cancer did not necessarily link the symptoms they were experiencing to the illness. This can be a healthy cognitive response but may also prevent children from reporting or seeking help when a symptom is a serious sign of the illness or a complication.

That children in both groups so often reported that they could bring symptoms onto themselves through own actions is important to be aware of. Children may feel

guilt and responsibility for symptoms or the illness which may in turn cause negative emotional reactions. Children with cancer may know that they are not to blame for their cancer, but may still feel responsible for becoming “more sick” (“maybe I have not eaten enough?”).

### **Cures**

The children in this study seemed quite aware of possibilities they had to alleviate or cure symptoms. Clinicians should be aware of the active coping strategies children use which may provide them with a sense of control and build on these as an addition to medical procedures and medication. Children may be quite open to try alternative methods such as e.g. relaxation techniques to alleviate symptoms.

### **Consequences**

The results of this study, where children with cancer reported that there were few consequences are, at first, surprising, because cancer is a life threatening illness, a fact that children often are aware of. One possible explanation mentioned earlier is the use of cognitive avoidance. Another possible explanation is that children with cancer relate consequences they are experiencing to the illness rather than the symptoms. Consequences such as becoming isolated from friends might be the same no matter whether the child has symptoms or not. Symptoms might be experienced as having few consequences as parents encourage their cancer sick child to live as normal as possible even though experiencing symptoms as activities might distract them from pain, nausea etc.

### **CONCLUSION**

The children in our study had a rich vocabulary to talk about many different somatic symptoms both in a general and specific way. Children do not seem to use “childish” terms. Children with cancer may have a more varied vocabulary for symptoms because they have more experience, but they do not seem to use more medical terms. Children had many different thoughts about the cause, cure and consequence of the 44 symptoms they were asked about that clinicians should be aware of, as this may result in different emotional reactions and coping responses. Children with cancer differed from healthy children in respect to focusing more on causes and less on consequences, believed in fewer cures and reported few social consequences of symptoms. Their answers may be the results of information given, their own

experiences and coping strategies used. Further studies are needed to examine how successful children are in communicating their somatic state during paediatric consultations. Therefore, the next step in our own research is to evaluate the effects of SiSom on number and types of symptoms addressed in patient-provider communication during paediatric consultations and its effect on symptom-related patient care.

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Table 1: Questions asked for each symptom

<b>Question posed</b>	
Understanding	Do you know what I mean when I say [the symptom, e.g.headache]? When does (the fictive child) feel like that?
Expression	What would (the fictive child) say if he/she were to tell anyone that he/she has [the symptom]?
Cause	What's the reason for ...[the symptom]
Consequence	What might happen when the fictive child has [the symptom]?
Cure	What helps/makes it better?

Table 2: Definitions of alternative terms with examples from children's answers.

<b>Category</b>	<b>Definition</b>	<b>Example (original symptom)</b>
<b>Synonyms</b>	The symptom term is the synonym of the original	"Are cold" ( <i>Feel cold</i> )
<b>More childlike</b>	A phrase that is unusual for adults	" My throat is worn out " ( <i>Get thirsty often</i> )
<b>More specific</b>		
Intensity	Specifies the intensity of the symptom	"Am very, very hot" ( <i>Am hot and sweaty</i> )
Bodypart	Specifies where the symptom is felt	"My gums bleed" ( <i>Bleeding in my mouth</i> )
Sensation	A more specific word for the sensation	"Feels like I can't breathe " ( <i>Can't breathe</i> )
<b>More generalized</b>	The symptom expression is a more general term	
Lay terms	The expression is a common "saying" in Norwegian	" Ants in the pants " ( <i>Can't unwind</i> )  "Puke" ( <i>Vomiting</i> )  "Being out of shape" ( <i>Can't manage to run as fast as before</i> )
Medical	Includes medical terms or an illness	"Constipation" ( <i>Can't poo</i> )  "Diarrhea" ( <i>Have runny poo and need to go all the time</i> )
Cause	The symptom term refers to the cause of the symptom	"Feel like I have eaten too much" ( <i>Have a tummy ache</i> )
Consequence	The symptom term refers to the consequence of the symptom.	"Need something to drink" ( <i>Have a dry mouth</i> )

Table 3: Number of total suggestions placed in each category for 44 symptoms

<b>Category</b>	<b>Healthy</b>	<b>Cancer</b>	<b>From both groups</b>
Synonyms	9	19	1
Specifying expressions			
Intensity	5	17	2
Bodypart	2	5	
Sensation	8	8	1
Generalizing expressions			
Lay terms	7	2	
Medical	1	4	
Cause	5	12	1
Consequence	1	2	
Childish expressions	2	2	
<b>Total</b>	<b>40</b>	<b>71</b>	<b>5</b>

Table 4: Causes, cures and consequences of symptoms with examples

<b>Dimension</b>	<b>Category</b>	<b>Symptom</b>	<b>Children's examples</b>
<b>Cause</b>	Medication	Feel nauseous	"When I get chemotherapy" (Cancer)
	Medical procedures	Feel dizzy	"After I have had narcosis" (cancer)
	Accident	Have bruises	"Tripped and fell" (Healthy)
	External factors- other's actions	Have a headache	"Somebody has hit you" (Cancer)
	Internal factors- own actions	Have pain in my arms and legs	"Having jumped too much on the trampoline" Cancer)
	Internal factors- psychological condition	Feel dizzy	"Having too many thoughts in the head" (Cancer)
	Bodily condition – pathological	It's hard to see	"You have got a virus in your eye" (Cancer)
Bodily condition – natural	Bleeding in my mouth	"If you loose a tooth" (Cancer)	
<b>Cure</b>	Medication	Get tired quickly	"You can try to get some medicine" (Healthy)
	Medical procedures	Can't breathe	"You might have an operation" (Cancer)
	Medical remedies	Have a wound	"Band aid" (Cancer)
	Internal – own actions	Have pain in my arms and legs	"Lay down and relax" (Healthy)
	External – others actions	Can't hold on when you need to wee	"Your mum might help you" (Cancer)
	Time will help	Hurts to wee	"You can only wait until it passes" (Cancer)
	No cure exists	Have a blocked nose	"Nothing helps" (Cancer)
<b>Consequence</b>	Psychological	Can't hold on when you need to wee	"You get embarrassed" (Cancer)
	Social	Have lots of hair on my body or face	"You might get teased" (Healthy)
	Remedial action	Sleep a lot during the day	"You have to be more active to keep yourself healthy" (Cancer)
	Accidents	Have shaky hands	"You might drop and destroy stuff" (Healthy)
	Functional problem	Get tired quickly	"It becomes impossible to eat" (Cancer)

Behaviour	Have a headache	“It might start to hurt so much that you might scream” (Healthy)
Other symptoms appear	Can’t manage to eat	“You become tired” (Healthy)
Death	Can’t manage to drink	“If you do not drink you might die” (Cancer)
There are no consequences	Sleep a lot during the day	“Nothing happens” (Cancer)

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