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Communication of Children Symptoms in Emergency: Classification of the Terminology

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Abstract. The significant part of non-urgent visits to the emergency highlight the necessity to advise people on the actions to take according to their symptoms. Although information sources are accessible through different channels their content often employs medical terminologies that are difficult to understand by laypersons. Our goal is to provide a terminology of the most common symptoms in pediatric emergency adapted to laypersons. This terminology is organized in a hierarchy by the mean of a card-sorting study. The resulting classification separates the symptoms into two main categories: "accident" and "illness" that are subdivided in 9 and 10 sub-categories. The study also revealed that some symptoms were not understood by the participants and had to be reformulated, confirming the importance of user-centered method. The classification resulting from this study will be evaluated through a tree-test.

Keywords. Health communication, access to information, consumer health information, terminology, symptoms, emergency health services, consumer behavior, consumer participation

1. Introduction

Many patients come to emergency for unnecessary reasons. Studies demonstrated that 30% of emergency department (ED) visits are in fact non-urgent [1]. The situation is similar in pediatric ED. This emphasizes the need to guide parents and help them to decide whether they should bring their children to emergency. Advices about the necessity to visit ED are usually given based on observed symptoms. The terminology employed to describe symptoms should be selected with care in order to be clearly understood by laypersons. Indeed, research in the field of consumer health vocabulary has demonstrated that consumers and health care professionals use different terminology to express themselves about health. This mismatch can hinder communication and health information seeking. In order to improve the communication

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of health information to consumers, through mHealth, appropriate terminology must be constructed with their help [2, 3].

Others researches have attempted to build lists of the most common symptoms. We found three recent studies aiming to estimate the prevalence of most common symptoms. One study was based on a list of 25 symptoms [4]. Another study evaluates the prevalence of 23 different symptoms [5]. The most recent research studied the prevalence of 44 self-reported symptoms based on literature search [6]. Other studies identified the most common symptoms asking adults about their present symptoms or in the past 2, 4 or 6 weeks [7]. If all these results are very valuable, none of these researches concerned the symptoms that brought people to pediatric ED.

Due to the lack of appropriate terminology we aim at constructing a terminology of the most common symptoms of pediatric ED at the University Hospitals of Geneva (HUG).

2. Methods

The construction started with the collection of an initial list of symptoms. In a second stage, we decided to organize this list into a hierarchy since it facilitates the search and exploration [8]. To build the hierarchy we relied on a web based card sorting tool. This user-centered method allows eliciting categorization by end-users [9, 10]. This method allows us to identify the categories inside the hierarchy but also to verify that participants understand all the symptoms names.

2.1. Construction of the List of Symptoms

An initial list of symptoms, containing over 200 symptoms, has been collected from a variation of the Canadian triage scale [11] adapted for the Geneva pediatric ED. During a year, triage nurses of the ED selected the most commonly reported symptoms by patient in the pediatric ED and end up with a list of 47 symptoms of illness and accident.

2.2. The Card-Sorting Test

The card-sorting task requested participants to group items (the 47 symptoms) in coherent categories from their perspective and to label them. One category was initially provided to allow participants to regroup the items they did not understand.

2.3. Population

According to recommendations on the minimal sample size required to conduct card-sorting study we decided to recruit at least 30 participants [12]. Participants were recruited through social networks over a period of a month. The inclusion criteria were: be at least 18 years old and the exclusion criteria were: working in a medical field.

2.4. Results Analysis

Before analyzes, semantically similar categories but labeled differently were merged into standardized categories. For example, both categories called “skin problems” and “skin” were combined into a single standardized category called “skin problems”.

To analyze the results, we used the Best Merge Method dendogram [13] provided by the software Optimal Workshop. This dendogram provides the proportion of participants that agree with each grouping.

We decided to keep only categories with at least 50% of participants’ agreement. For symptoms for which no agreement was observed (less than 50%), we asked an ED physician to classify them within the categories established by the participants or to create new categories. We also discussed how to classify the symptoms that participants did not understand, and asked the physician to validate, or correct when necessary, the categorization made by the participants.

3. Results

The study took place from 18 August to 26 September 2016. The test has been completed by 35 participants. This sample included 30 women (86%) and 5 men (14%), 13 of them having children (37%) and 22 do not (63%).

On the 25 categories proposed by the dendogram, we kept 8 categories for which at least 50% of participants agreed. These categories are: 1) mouth / nose / ear / throat 2) digestion / intestine 3) urology / private parts 4) fever 5) skin problems 6) articulations / motricity 7) headache 8) accident.

Eight symptoms led to many disagreements: allergic reaction, depression/anxiety/crisis, cough/difficulty breathing, headache, bloody nose, oral thrush, hernia and whitlow. Four symptoms (oral thrush, whitlow, colic, hernia) were classified in the category “I do not know what that means” by up to 23% of participants.

As recommended, hierarchy should be limited to 8 items per level to provide effective navigation [8], therefore categories containing more than 8 items were split into subcategories. First, as participants created an “accident” category, we decided to also create an “illness” category to distinguish the two main types of symptoms in a first level. In the accident category, we created two sub-categories to group some similar symptoms and to avoid having too many items: 1) swallowed something/choked 2) sting. We also created the subcategory “rash” to reduce the number of items in the “skin problems” category. The same problem was avoided by creating the subcategory “mouth and throat”.

Other changes were made following the discussion with the ED physician. Under the illness category, a “queasiness” category was created in order to insert the symptoms “queasiness without fever” and “queasiness with fever” previously located in the “fever” category. The category “mouth/nose/ear/throat” was lightly changed for “mouth/nose/ear/eyes” in order to reflect that the “eye” symptom also belong to the category. The symptoms, for which no agreement has been observed (less than 50%), were renamed when necessary and placed in the most suited existing category. Some symptoms were recognized as diagnostics and were renamed to match the associated symptoms (allergic reaction: “swollen lips/tongue” and “red patches and itching”, hernia: “genital swelling” and “swelling in the groin”, colic: “baby colic/crying crises”, whitlow: “finger/nail infection”, oral thrush: “oral thrush/white plates”). The three

symptoms that were not linked to any category were placed under the illness category (e.g. cough/difficulty breathing). Finally, composite symptoms composed of two sub-symptoms (e.g. rash with fever) were placed in several categories (e.g. "skin problems" and "fever").

The final tree is presented in figure 1. Nodes in blue on the diagram are branches. Nodes in orange are leafs. In our case, the depth is of 4 levels and the breadth range from 2 to 10 nodes per level. The hierarchy is quite unbalanced since most of the nodes are regrouped under the illness category.

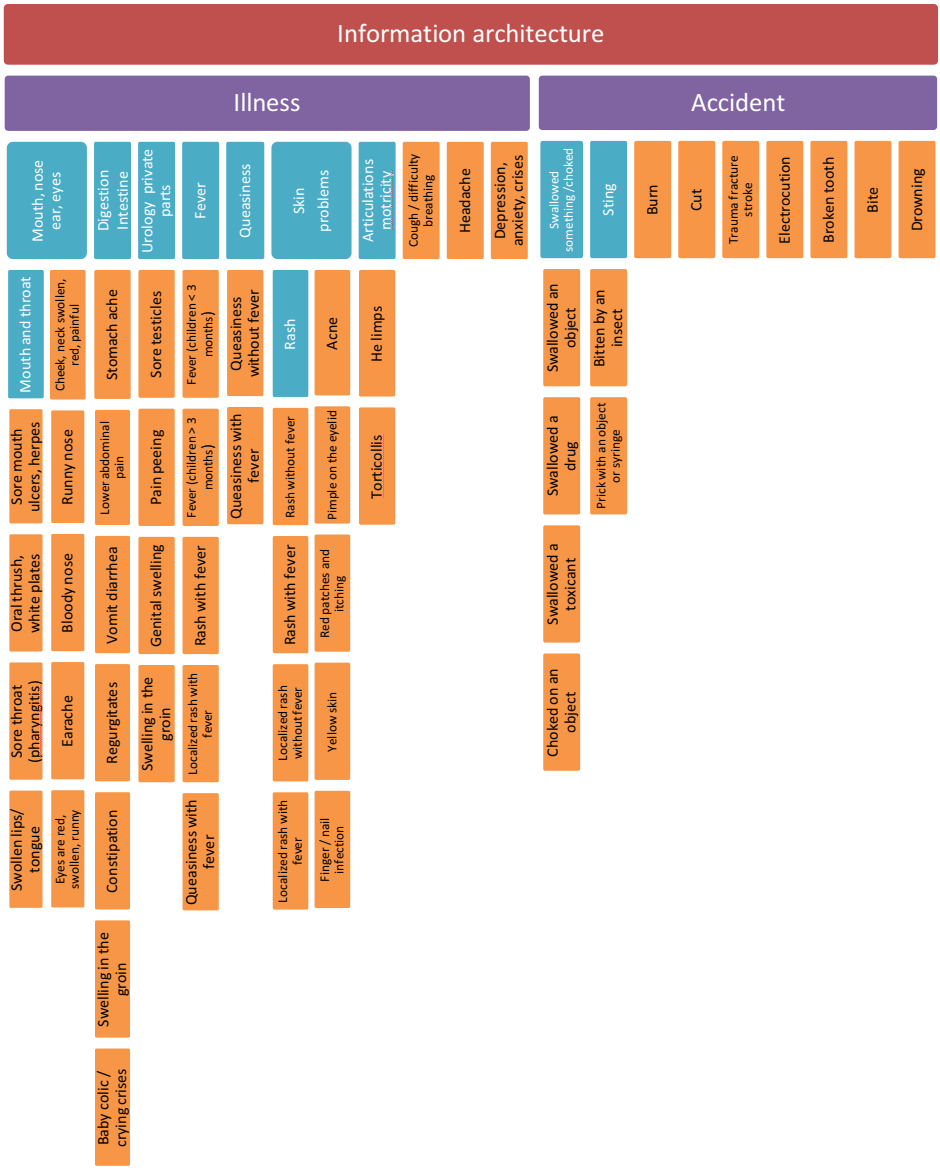

Figure 1. Terminology tree.

4. Discussion

Laypersons have difficulty to find information about their children's symptoms due to inappropriate terminology [14]. This underlines the importance of developing terminologies adapted to specific audience. A limitation of our study is that the initial list of symptoms is based on the Canadian triage scale. The ideal would have been to create a list of symptoms based on terms provided directly by laypersons who consult at the emergency department. Independently of the choice of the initial terminology, the organization of the symptoms made through card-sorting improves the findability of information provided to patients. Before implementing this terminology in a mobile application, the symptoms hierarchy will be tested through a tree-test in a further study to ensure its effectiveness.

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