



University of São Paulo

ADOLESCENTS' UNDERSTANDING OF CHEMOTHERAPY- RELATED ADVERSE EVENTS: A CONCEPT ELICITATION STUDY

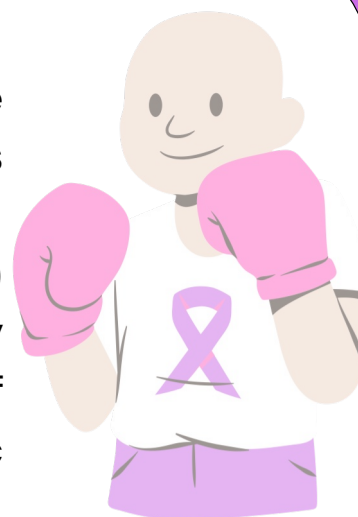
FERNANDA M. SILVA-RODRIGUES¹, PAMELA S. HINDS², LUCILA CASTANHEIRA NASCIMENTO¹

1.University of São Paulo, Brazil ; 2. Children's National Health System, USA



INTRODUCTION

Cancer in adolescence poses unique challenges due to delayed diagnosis and poorer treatment adherence. In Brazil, cancer is the second leading cause of death among adolescents, with common types including lymphomas, leukemias, and Central Nervous System tumors. Chemotherapy, the prevalent treatment, leads to adverse events (AEs) like fatigue, nausea, and mood changes, significantly impacting quality of life. This study aims to document and validate the understanding of chemotherapy-related AEs in Brazilian adolescents using the Pediatric Patient-Reported Outcomes version of the CTCAE .



OBJECTIVE

To document adolescents' understanding of chemotherapy-related core adverse events from the Pediatric Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events (Ped-PRO-CTCAE®) and thus begin the validation process of this tool's items with Brazilian adolescents.

METHODS

This prospective concept elicitation study used descriptive cognitive interviewing (CI) to explore adolescents' understanding of the adverse events of chemotherapy.

RESULTS

Adolescents reviewed and named Adverse Events (AEs) and provided detailed descriptions of **physical** and **emotional** AEs experienced during chemotherapy.

Gastrointestinal AEs: the most detailed. Nausea, vomiting, constipation, diarrhea, pain, and mucositis were identified. Nausea and vomiting were related to specific chemotherapy drugs.

Pain: Participants could name pain sites and characteristics, including generalized pain and pain related to specific drugs.



Sadness and Depression: adolescents understood this terms, and described feelings of sadness and sensitivity related to chemotherapy. Some participants reported increased sensitivity and mood swings due to treatment.

Impact of Physical Changes: hair loss was a significant situational factor affecting self-esteem and causing emotional distress.

Adolescents demonstrated an understanding of the cause-and-effect relationship between chemotherapy drugs and adverse events (AEs), identifying precipitating factors and accurately describing the duration and temporal aspects of these events.

Core terms extracted from the Pediatric PRO-CTCAE** (adapted to Brazilian adolescents)			
1	Abdominal pain (Belly pain)	9	Fever
2	Anorexia (Don't want to eat your meal)	10	Headache
3	Anxiety (Worried or nervous)	11	Insomnia (Problems sleeping)
4	Constipation (Cannot poop)	12	Oral Mucositis (Sores in your mouth or throat)
5	Cough	13	Nausea (Feeling sick to your stomach)
6	Depression (Sad or unhappy feelings)	14	Pain
7	Diarrhea (Runny or watery poop)	15	Peripheral neuropathy (Numbness or tingly feeling in your hands or feet)
8	Fatigue (Feeling tired)	16	Vomiting (Throwing up)

Examples of questions asked during Cognitive Interviewing	
A.	Do you know what is ABDOMINAL PAIN (if the adolescent says no, use "belly pain")?
a.1	Where is the abdomen?
a.2	What other name could you give to this part of your body?
a.3	In the past seven days, have you felt this pain? (If yes) How did it feel? For how long did you feel this pain?
B.	Have you ever felt SAD or UNHAPPY FEELINGS after chemotherapy?
b.1	In the past seven days, how bad were your sad/unhappy feelings?
b.2	Please, tell me more about these feelings.

Figure: Core items and cognitive interviewing questions



CONCLUSIONS

The study highlights the importance of including adolescents' voices in AE assessments to improve symptom management and quality of life. Nurses play a crucial role in managing these AEs and educating patients and families. This research also supports the validation of a tool for reporting chemotherapy-related AEs in Brazilian adolescents.

REFERENCES

Pinheiro LC, McFatrigh M, Lucas N, Walker JS, Withycombe JS, Hinds PS, et al. Child and adolescent self-report symptom measurement in pediatric oncology research: a systematic literature review. Qual Life Res. 2018 Feb;27(2):291–319.
Reeve BB, McFatrigh M, Pinheiro LC, Weaver MS, Sung L, Withycombe JS, Baker JN, Mack JW, Waldron MK, Gibson D, Tomlinson D, Freyer DR, Mowbray C, Jacobs S, Palma D, Martens CE, Gold SH, Jackson KD, Hinds PS. Eliciting the child's voice in adverse event reporting in oncology trials: Cognitive interview findings from the Pediatric Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events initiative. Pediatr Blood Cancer. 2017 Mar;64(3):10.1002/pbc.26261.