

Previous pain experiences: the voice of children with cancer and their parents

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Abstract

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Abstract

Introduction

Pain is a common and distressing symptom among children with cancer and has a significant impact on their quality of life and psychological well-being. Pain assessment in these patients is often complicated by the subjective nature of pain perception and the difficulty in communicating symptoms. For this reason, pain assessment should be based on accurate anamnesis of the previous experiences in order to achieve a patient-specific overview of their experience. The aim of this study was to record children's previous pain experience and determine their understanding of pain and their treatment preferences.

Methods

This qualitative study was conducted by administering the Italian version of the "Pain Experience History" ¹ on a consecutive series of patients being treated in the Pediatric Unit at "Istituto Nazionale dei Tumori" of Milan. Informed consent was provided by 26 children, aged between 4 and 14, and their parents. The pain experience history questionnaire presents parallel forms for children and parents; it features open-ended questions to assess children's understanding of the word "pain", previous experiences of pain, ways of communicating pain, and preferences for treatment. Krippendorff's content analysis constitutes the framework of data research.

Results

Each child is different from the other and has different expectations especially on the management of their pain. Questionnaires highlight the past pain experience and the treatment preferences of each child. In general, they described pain as "a bad thing" or "suffering", while the most recurring expressions were "I feel bad", "it makes me cry" and "it hurts". Their experiences before hospitalization included small traumas, headaches, stomach-aches, or procedural pain during the diagnosis. If the pain was caused by their condition, they referred to it as inner pain. When they felt pain, children preferred to distract themselves, seeking tranquillity, closeness of their parents and, if the pain did not stop, medications. Results showed that children preferred not to be "nagged" or disturbed. Children, even the youngest, demanded precise answers about their condition. The results showed that some children were reluctant to talk about their pain and preferred to stay silent until it became unbearable. For instance, some children answered that when they feel pain they tell "no one, only mom when it's really bad", or they "suffer in silence", or "It depends. At first no, I wait to see if it decreases". In these cases, the tool offers the possibility of obtaining information that is difficult to infer otherwise, allowing precise and timely intervention. As for their parents, their answers generally confirm and further contextualize children's pain experience.

Conclusions

The Pain Experience History questionnaire is a simple tool to administer, flexible and understandable by both children and parents. Discussing previous experiences of pain may promote a more effective approach to pain management from nurses and parents. In conclusion the children's answers provided insight into their coping strategies for pain.

Reference

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