

# The flavor of chemotherapy

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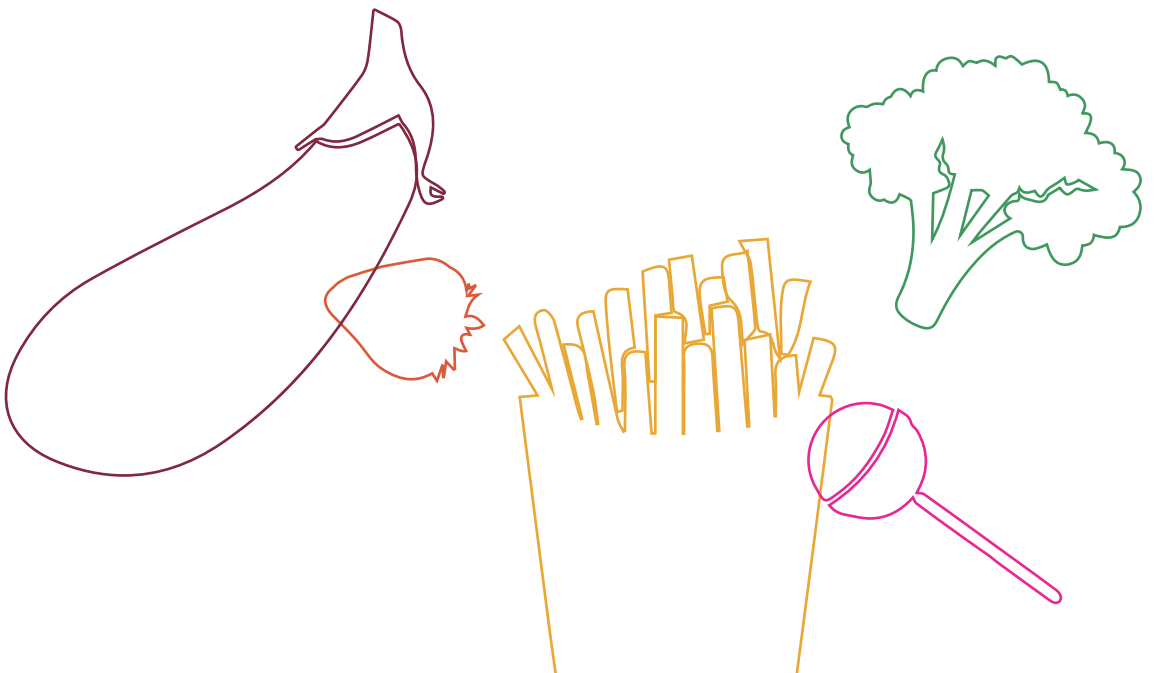
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# 9

Impact paragraph



A cancer diagnosis and subsequent treatment have an enormous impact on a child's life. Consequently, physical, psychological, social, and spiritual well-being of the child is affected <sup>1</sup>. Survival rates of children with cancer have increased over the past decades and as a result, pediatric oncology care is no longer focused solely on survival <sup>2-4</sup>. Surviving childhood cancer requires very intense treatment and can have both acute and longer-term effects on a child's health and well-being <sup>5-7</sup>. Therefore, more attention is directed towards managing side effects during treatment and late effects in survivorship, which is reflected in the mission statement of the Princess Máxima Center: *'Curing every child with cancer, with an optimal quality of life'*.

Nutritional care should be highly prioritized in advancing care of children with cancer, as it can have a profound impact on both short- and long-term outcomes <sup>8-10</sup>. Such nutritional care or counseling should be provided taking potential taste and smell changes into account. Unfortunately, this is not a fixture of (pediatric oncology) clinical practice yet. Developing and implementing such counseling seems timely. Until recently, hardly any data was available regarding changes in smell and taste in children with cancer, but since the COVID-19 pandemic the potential impact of such chemosensory changes on eating behavior and quality of life are more readily recognized <sup>11-14</sup>.

The aim of this dissertation was to expand our knowledge and understanding of children's changes in smell and taste during treatment for childhood cancer. Apart from contributing to a body of scientific evidence, the results described in this thesis may lead to the development of new interventions and (dietary) recommendations in the future. In this chapter, I will discuss the scientific impact of our research by addressing its relevance for children with cancer and their families specifically, but also for health care professionals and society. Moreover, the dissemination of our knowledge is addressed, ending with an overall conclusion.

## **RELEVANCE FOR CHILDREN WITH CANCER – QUALITY OF LIFE**

The results of this thesis are relevant for the child with cancer. I found that smell and taste disturbances are highly present among children with cancer, although these disturbances vary between individuals. Some patients displayed heightened chemosensory function, whereas other patients had decreased chemosensory function.

Smell sensitivity seems increased during treatment, particularly for children with ALL receiving corticosteroids. However, this was not a consistent finding across studies. While our feasibility study indicated heightened smell sensitivity in patients compared to controls, our longitudinal study did not show significant changes in smell sensitivity during treatment (although an increase in maintenance phase in children with ALL). However, we did find that an experienced (i.e., self-reported) increase in smell sensitivity was highly prevalent as well as a generally increased ability to identify odors (relative to norm scores) at each time point.

Sweet, bitter, and overall taste scores tended to increase shortly after a cycle of chemotherapy, but in contrast to smell function, taste function generally seems lowered in children during active treatment with chemotherapy. Based on the Taste Strips test, taste loss had an occurrence rate of approximately 20%. Self-reported changes in taste occurred in nearly 80% of the children during treatment, although these changes were often described as “food tasting different than before” rather than changes in taste sensitivity or perceived taste intensity. Regardless of their presentation, chemotherapy-induced taste (and smell) changes affect eating behavior and (quality of) daily lives of children with cancer and their families.

In the Netherlands, children and their parents do not receive any standardized information regarding the changes in smell and taste that occur during chemotherapy. This is perhaps not very surprising. When a child has just received a cancer diagnosis, the parents' main focus is on questions regarding prognosis, type of treatment, hospital admissions, medication, lab results, and so on. Most parents are initially unaware of the risk for nutritional complications, including changes in smell and taste, that are associated with chemotherapy. Further, as chemosensory changes are non-life threatening, they are rarely discussed during regular consultations. Therefore, children and parents end up experimenting; that is, trying out several strategies to cope with taste, smell, and eating problems. They manage through trial and error but not without unnecessary disappointments and frustration. The present results give valuable input for educating children and parents at the start of treatment so that they know what to expect and are provided with effective coping strategies. I believe that this research will have a large influence on the daily (quality of) life of children with cancer, on their pleasure of eating, and on their nutritional status and clinical outcomes.

Unlike older adults who survive cancer, childhood cancer survivors have a whole life ahead of them. Their adult life is marked by an increased risk for various non-communicable diseases. For example, childhood cancer survivors have an additional risk of developing cardiometabolic disease<sup>15-17</sup>. Treatment trajectories for childhood cancer appear to be a period in which children develop unhealthy eating habits and food preferences<sup>18</sup>. Parents are already happy if their child eats something, even if it is just ice cream or fries. Studies suggest that long-term changes in chemosensory function and appetite may affect eating habits in survivorship<sup>19</sup>. In addition, adverse effects during treatment (e.g., nausea, vomiting, mucositis) have been associated with reduced dietary intake and pleasure, consequently changing dietary patterns which may become longer-term habits<sup>20-23</sup>. Unfortunately, such acquired unhealthy eating habits (e.g., decreased fruit and vegetable intake, increased junk food consumption and portion sizes) have been proven difficult to unlearn in survivorship<sup>18, 24, 25</sup>. Therefore, research into the development of tailor-made dietary recommendations to alleviate treatment-related side effects, but also adequate nutrition education during and after treatment, is relevant for patients as well as their families and society.

## **RELEVANCE FOR HEALTH CARE PROFESSIONALS – QUALITY OF CARE**

The findings of this thesis also apply to pediatric oncology health care professionals including doctors, nurses, dietitians, nutrition assistants, chefs, psychologists, pedagogical staff, and all other team members involved. Apart from informing and educating patients and their parents, health care professionals should be educated too. At the moment, there is little knowledge and awareness about smell and taste changes in children with cancer undergoing chemotherapy. Therefore, it is necessary to share the results of this thesis at the various departments of the Princess Máxima Center, as well as its shared care centers (i.e., pediatric departments within hospitals across the Netherlands that closely work with the Princess Máxima Center) and the Children's Comfort Team (i.e., health care professionals providing home care), to provide the best possible quality of care.

## AND NOW?

All studies including children with cancer as described in this thesis were designed in close collaboration with parents of patients via the Dutch Childhood Cancer Organization (VKN). For example, patient information letters and interview guides were reviewed and commented upon by the VKN before I used these forms and letters in the studies. Since this thesis has been finalized, we will share our results and knowledge with this audience via their monthly newsletter and quarterly magazine (Attent). Moreover, a section about changes in smell and taste will be added to the information diary that children and parents receive at the start of treatment.

Apart from sharing our knowledge at several departments and shared care center of the Princess Máxima Center, as mentioned before, our results will be (and have been) shared through publications in peer-reviewed journals and presentations at international congresses.

Lastly, I will collaborate with Institute Paul Bocuse in Lyon to further work on exploring culinary adaptations for children with cancer specifically. Through this, we hope to find approaches to alleviate the detrimental effects of chemosensory changes on food intake, thereby improving nutritional status and quality of life of children with cancer.

## CONCLUSION

In sum, this dissertation enhances our understanding of how smell and taste function might change in children with cancer undergoing chemotherapy. Although our findings warrant further investigation, they can be used to educate patients, their families, and health care professionals regarding expectations and coping strategies of smell and taste alterations. Moreover, it provides a useful starting point for new (dietary) recommendations and interventions, including studying whether counseling by a dietitian regarding smell and taste changes is effective in improving food intake, nutritional status, and quality of life of children with cancer.

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