

No place like home? Focusgroups in children and parents on transferring part of oncology care to home

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Background/introduction

In the Netherlands, yearly around 600 children are diagnosed with cancer. As treatment and survival rates improve, the overall 5- year survival rate is currently around 85%, the largest part of the treatment with chemotherapy still has to be administered in a specialized hospital. Children are obliged to visit the hospital regularly which results in missing out on school and social activities. This makes it difficult to continue a normal lifestyle which influences the quality of life. To attend to these visits, parents cannot go to work and feel a huge sense of responsibility towards the child's care, and a sense of failure to the other siblings. As chemotherapy is still mainly administered in the hospital, supportive care such as tube feeding- and antibiotic care are administered at home frequently, by pediatric homecare nurses. Would it be possible to extend this to administering part of the oncological treatment at home? What are the parent and child preferences?



Aim

The aim of this study was to explore the thoughts, ideas and wishes of children with cancer and their parents according to hospital transferred care to the home environment.



Method

A semi-structured questionnaire was developed to ask children > 12 years and parents of children < 12 years their opinion about this topic. Recruitment of children and parents for participation was carried out by nurse practitioners from all wards of the Princess Máxima center, e.g. hemato oncology, solid oncology and neuro oncology. Children were included if they were > 6 weeks on treatment and within a year of finishing treatment. Written Informed consent was obtained from the included subjects. The medical ethics committee waived the need for official approval of the study

Results

Eighteen parents were included in 3 focus groups, each containing 6 parents. Group 1 did not receive homecare, group 2 already received homecare, and group 3 had children who had finished active treatment < 1 year. 13 children were included and interviewed.

Ninety percent of the parents and all the children stated that homecare would improve their quality of life. Parents were more reluctant than children, because of safety and quality aspects especially parents of children who had finished their treatment. Parents who had no experience with homecare, were most interested in homecare and saw the least restrictions. Children felt strongly that their care could be transferred to their home since it would allow them more valuable time outside of the hospital.



Future

The majority of parents and children are in favor of transferring part of pediatric oncology care to the home setting, if safety and quality of homecare is guaranteed. Long infusions and treatment with high risk of allergic reactions were called unsuitable for the home situation. Children were overall more enthusiastic than parents. Parents main concerns were about mentioned as quality and safety of the home care. Children were most worried about the home care nurses' skills accessing the porth a cath. Possibilities on what care to transfer will be discussed in the broader homecare working group appreciating the wishes of children and parents.



Conclusions

- The focusgroups conclude that the majority of parents and children are in favor of transferring part of pediatric oncology care to the home setting,
- Homesetting is thought safe if safety and quality of homecare is guaranteed.
- Possibilities on what care to transfer will be discussed in the broader homecare working group appreciating the wishes of children and parents
- Future pilot studies will be started in transferring certain chemotherapy to home in accordance with parents wishes and in accordance with safety and quality control
- Finances will be checked considering possibilities to transfer care to home, evaluation of this care and eventually implementation