Information till föräldrar som har barn med cancer

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Akademisk avhandling

som med vederbörligt tillstånd av Rektor vid Umeå universitet för avläggande av medicine doktorsexamen framläggs till offentligt förvar i Vårdvetarhusets aula, fredagen den 31 maj, kl. 09:00. Avhandlingen kommer att försvaras på svenska.

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Information to parents of children with cancer

Abstract

Background. Parents of children with cancer experience a life situation characterised by uncertainty and worries, and they face ongoing social and emotional challenges. Compared to parents of healthy children, they also experience increased levels of perceived stress and they suffer to a greater extent from post-traumatic stress symptoms. Even though information about the child’s disease is crucial for parents, parents still experience low satisfaction with the information given to them.

Aim. The aim of this thesis was to, within the field of paediatric oncology care, describe health care professionals’ and parents’ experiences from information, study their joint interaction and describe experiences and effects from an intervention based on person-centered information to parents.

Methods. For study I–III, focus group interviews (I, II), individual interviews (II, III), and participant observations (III) were used. Participants were 20 health care professionals (I), 14 parents of children with cancer (II) and 25 health care professionals and 25 parents (III). Data were analysed by qualitative content analysis (I, II) and discursive psychology (III). In study IV, an intervention for person-centered information was tested on 8 parents using a single-case experimental design. Data were collected with qualitative interviews and web questionnaires. Outcome measures were perceived stress, physical symptoms from stress, anxiety, depression, and satisfaction with information.

Results. In study I, the analysis resulted in two themes, Matching the amount of information to the parents’ needs, which dealt with differences in the amount of information provided to parents according to the health care professionals’ assessment of parental needs, and Navigating through a vague structure, which was about shortcomings in responsibilities, setting, timing, and language when parents were informed. In study II, two themes were constructed. Feeling acknowledged as a person of significance was about feeling safe and secure, having one’s hopes supported and getting relief from other families. This was accentuated early in the treatment trajectory. Feeling like an unwelcome guest was about feeling abandoned at important milestones, feeling forced to nag for information and being burdened by informing others. In study III, the health care professionals used interpretative repertoires that were child, parent, or family oriented, which mirrored the primary focus of the interaction. Parents used repertoires as a spokesperson, an observer, or a family member. The combination of the repertoires steered the interaction. In study IV, parents reported a high satisfaction with the person-centered information intervention and perceived benefits from having their own time to discuss the child’s disease and pose questions that they otherwise would not have an opportunity to ask. No effects from the intervention were demonstrated on perceived stress, physical symptoms of stress, anxiety, and depressive mood.

Conclusion. To improve information to parents of children with cancer, a central task is to assess the amount of and what information given to parents, pay attention to possible differences in information needs between parents and children, as well as to organise the care so that the responsibilities are clear and that parents are met in a calm setting. Improvements at important milestones during the illness period should be prioritised. A person-centered information intervention is perceived as beneficial by parents, however, its effect on perceived parental stress has further to be investigated.

Keywords

Discursive psychology, focus groups, health-care professionals, interventions, parents, paediatric oncology nursing, perceived stress, person-centered information, qualitative content analysis, qualitative interviews, single-case experimental designs.