

ABSTRACT

This thesis "*The Needs of Parents during End-of-Life Care for Terminally Ill Child*" deals with the needs of families in which a child had died from a serious illness. The main goal of this thesis is to map the needs of parents caring for a terminally ill child during the course of the illness, the time of dying, and after the death of the child. The thesis also analyses the source of risk factors occurring while parents cope with care provision.

The theoretical part of this thesis focuses on the loss of a child. The opening chapter is devoted to paediatric palliative care, including an assessment of the current situation in the Czech Republic. Based on the available sources, grief theories are described. Furthermore, the effect of the death of a child on the family is mapped, including the impact on the parent's relationship and the way parents cope with their grief. The last section of this part covers the possible reactions of parents to their loss.

The empirical part detects the needs of parents caring for a terminally ill child. It maps the mechanisms which help parents to cope when caring for their child or dealing with their loss. It also identifies the risk factors influencing on the ability to cope with the care provision. The data were collected using qualitative research techniques. The survey consists of nine in-depth interviews with bereaved parents; collected data were analysed using the grounded theory techniques.

Two categories based on key findings were identified: *the preservation of one's identity of parent* and *the influence of the surroundings*. Factors influencing on parents during end-of-life care for their child and after his/her death are listed and discussed. The need to be with the child and the need to take care of the child were identified as the main needs of the bereaved parents. The category *the influence of the surroundings* is characterized by the support provided by the health professionals taking care of the child and the family. Issues identified by the parents included, among others, the issue of doctor-parent communication, the lack of psychological support, and the importance of support provided to parents after the child's death.

Key words: terminally ill child, paediatric palliative care, loss of a child, bereavement, death, family, needs of bereaved parents