

Publication

Missing life stories. The narratives of palliative patients, parents and physicians in paediatric oncology

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Abstract Illness narratives have become very popular. The stories of children, however, are rarely ever studied. This paper aims to provide insight into how children, parents and physicians make sense of progressive childhood cancer. It also explores how this meaning-giving process interacts with cultural dominant stories on cancer and dying. The presented data come from 16 open-ended face-to-face interviews with palliative paediatric patients, their parents and physicians. The interviews were carried out in eight paediatric oncology centres in Switzerland. Data analysis followed Arthur Frank's dialogical narrative analysis. Quest narratives were relatively rare compared to both chaos and restitution stories. All participants welcomed chaos stories as a liminal haven between quest and restitution. The possibility that the child could die was either ignored or briefly contemplated, but then immediately pushed away. Except for one patient, children never directly addressed the topic of death. The way in which death was presented raises important questions about how the social discourse on dying is framed in terms of choice, autonomy and individuality. This discourse not only determines the way in which children and adults relate to the minor's death, it also constitutes an obstacle to children's participation in decision-making.

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