



UNIVERSITY OF GOTHENBURG

IMPROVING CARE OF CHILDREN WITH CANCER IN EGYPT

AKADEMISK AVHANDLING

som för avläggande av medicine doktorsexamen vid Sahlgrenska Akademin vid Göteborgs Universitet offentligen försvaras i Hjärtats aula på SU/Sahlgrenska Universitetssjukhuset, Vita stråket 12

Fredagen den 10 januari kl. 09.00

av

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Avhandlingen baseras på följande delarbeten:

- I. **El Malla H**, Kreicbergs U, Steineck G, Wilderäng U, El Sayed Elborai Y, Ylitalo N. Parental trust in health care – a prospective study from the Children’s Cancer Hospital in Egypt. *Psychooncology*. 2013;22:548-54.
- II. **El Malla H**, Kreicbergs U, Ylitalo Helm N, Wilderäng U, El Sayed Elborai Y, Elshami M, Steineck G. Cancer disclosure – account from a pediatric oncology ward in Egypt. *Submitted*.
- III. **El Malla H**, Ylitalo Helm N, Wilderäng U, El Sayed Elborai Y, Steineck G, Kreicbergs U. Adherence to medication: a nation-wide study from the Children’s Cancer Hospital, Egypt. *World Journal of Psychiatry*. 2013; 3:25-33.
- IV. **El Malla H**, Kreicbergs U, Steineck G, Aboulnaga S, Elshami M, El Sayed Elborai Y, Wilderäng U, Ylitalo Helm N. Advances in pediatric oncology – a five-year nation-wide survival follow-up at the Children’s Cancer Hospital in Egypt. *Submitted*.

ABSTRACT

Aims: More than 70 percent of the children diagnosed with cancer in Egypt die every year. In Sweden the corresponding figure is close to 20 percent. The aims of this study was to investigate psycho-oncological predictors of mortality, parental perception of the care their child received as well as of the health care professionals, in order to improve care of children with cancer. The main hypothesis was that parental degree of trust affects a child's adherence to treatment, dose intensity and therefore survival.

Methods: During an 18-month preparatory phase, we carried out in-depth interviews, participant observations at the hospital, construction of two study-specific questionnaires, face-to-face validation of the questionnaires, and thereafter, a pilot study testing the logistics. Following that, the main data collection was carried out during the recruitment period of February to September in 2008. The eligible study population was parents of children newly diagnosed with a malignancy and admitted to receive a first chemotherapy cycle at the Children's Cancer Hospital in Cairo, Egypt. The parents were approached twice, first prior to their child's first chemotherapy cycle and then again before the third. Among the 313 eligible parents, 304 (97%) answered the first questionnaire, and 281 (92%) the second one.

Results: We found that parents reported a higher degree of trust in the medical care provided (RR 32.0; 95% CI 15.2-67.7) when they were met with care by their child's physician. Having received information concerning the disease (RR 13.2; 95% CI 7.8-22.3) and treatment (RR 17.2; 95% CI 9.5-31.4) resulted in higher trust in the health care and the physicians. Also, we found that 72 percent ($n=219/304$) of the parents had their child's disease disclosed by the physician. Among those, 39 percent ($n=85/219$) of the children were present during the conversation. Less than half of those children (45%) were below the age of 5. Also, 68 percent ($n=123/181$) of the parents reported that their child did not take the prescribed medication while at home and the two main predictors reported by the parents were child's resistance (90%, $n=111/123$) and inadequate information provided (81%, $n=100/123$). Finally, five years after the study was conducted, we observed a survival rate of 58 percent ($n=176/304$) with a 10 percent lost to follow-up. Among the studied children, we could, however, not relate the mortality to any of the psychosocial predictors addressed in this thesis.

Conclusion: Our main hypothesis that the degree of parental trust in the health care system and physicians affects the child's adherence to treatment, dose intensity, and thereby the survival rate, was not confirmed. We found an association between information provision and how it is provided with trust and adherence, yet none of these predictors were associated with the obtained survival rates. The observed survival rate of the children in our group is 58 percent, with an addition of 10 percent lost to follow-up. This is an increase as compared to official statistics of earlier years. Adherence to medication while at home was associated with parental degree of trust in physicians and health care professionals, but not with survival rate. We found an association between whether before the child's first chemotherapy cycle 1) information to parents was provided or not, and 2) how it was provided, with the degree of trust reported by the parents before the child's third chemotherapy cycle.

Keywords: Childhood cancers, psychosocial oncology, cancer care in Egypt

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ISBN: 978-91-628-8730-8

<http://hdl.handle.net/2077/34400>