

Experiences with Lukashuset - the first hospice for children and adolescents in Denmark

Mette Raunkjær¹, Susan Cawley², Thomas Feveile², Signe Hørlück², Karen Marie Kjeldsen², Nanette Quistorff², Charlotte Reinhart Pedersen² and Mark Rogers².

1. REHPA, The Danish Knowledge Centre for Rehabilitation and Palliative Care, Department of Clinical Research, University of Southern Denmark
2. Sankt Lukas Stiftelsen, Lukashuset

Declaration of conflicts of interests: The authors have nothing to declare.

Study aim

To provide an overview of the characteristics of the children and adolescents admitted to Lukashuset (LH) children's hospice, and to describe the families' experiences with their hospice stay.

Background

In Denmark the yearly average mortality of children (0-18 year incl.) from 2012-2014 was 281, where 110 die before 1 year of age (1). Paediatric palliative care (PPC) is developing rapidly in Denmark. LH (the first hospice for children and adolescents) and five regional palliative care teams for children and adolescents were established in 2015-2016.

Methods

Data collected from patient records and personal interviews was included in 2 sub-studies.

1. A quantitative overview of the children and adolescents admitted with a descriptive analysis of the data.
2. A qualitative exploratory interview study with the parents/close relatives. The theoretical framework was quality of life (QoL) and everyday life theory (2-3). The analysis approach was meaning condensation (4).

The data was collected between 01.11.2015 and 30.09.2016. The study was approved by the Danish Data Protection Agency and Danish Research Ethics Committees. The study complies with the WMA Declaration of Helsinki.

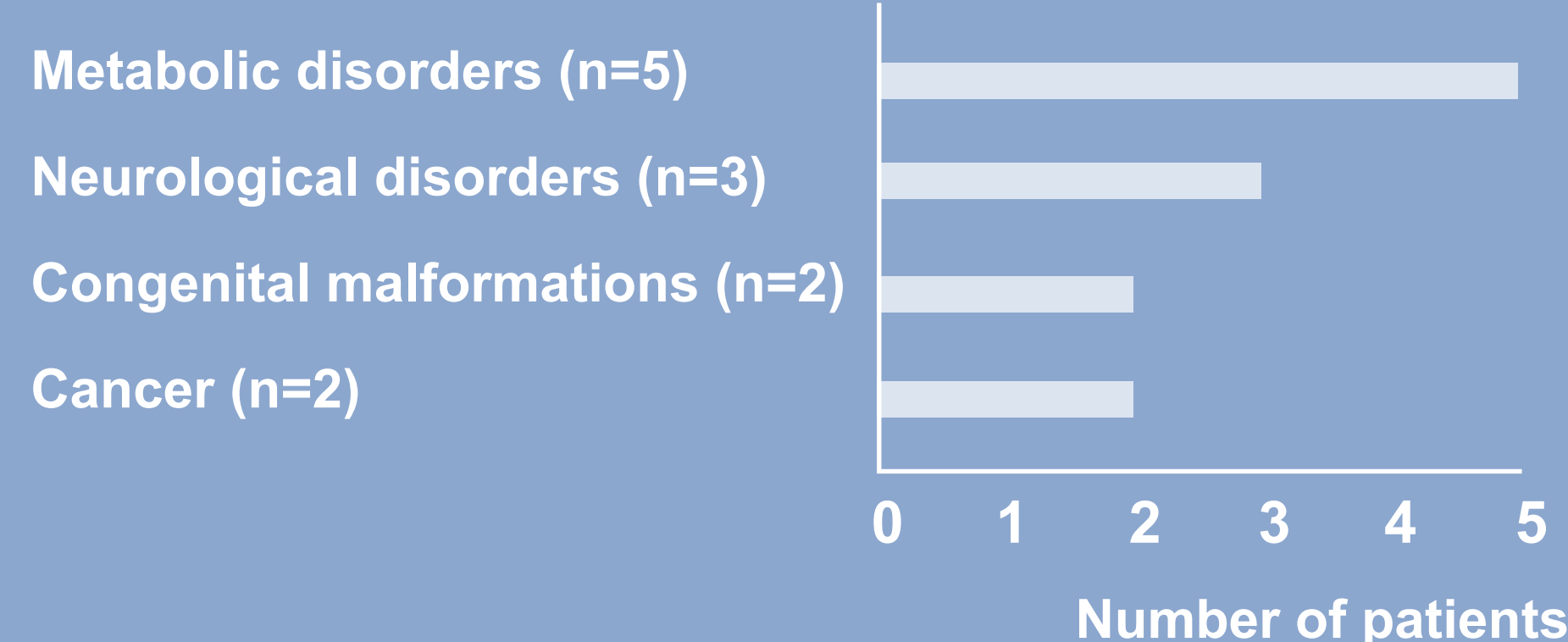
Results of sub-study 1

12 children and adolescents were admitted.

Table 1: Ages of the admitted children/adolescents

Number	Age/years
6	< 1
2	1-3
2	4-9
2	10-17

Figure 2: Diagnoses



The average length of admission was 56.6 days. 4 of the admissions were between 122-242 days. Excluding those 4 the average length of admission was 12.8 days. For every 24 hours a child was admitted, 2.3 persons were additionally admitted. 7 of the children died during the study period - 4 in LH, 2 in hospital and 1 at home.

Results sub-study 2

Interviews were conducted with 11 parents and 1 close relative (6 families). The following conditions had a positive impact on QoL, life stability and the everyday life of the families:

"It is peaceful and there is space at LH. You feel well taken care of and that the care is personalized for our family. I think the other families also feel the same way, even though their needs are different to ours." (Parent)

- The professionals' skills in caring for and treating the child both in acute and stable periods.
- The cooperation between the professionals in LH and the hospital doctors.
- Individualised palliative care services.
- The balance between receiving help and having privacy.
- Respite-care, e.g. help with daily tasks, child-minding at night to give parents the opportunity to sleep.
- The relationships with and the continuous possibility to talk to the professionals at LH.
- The volunteers', the clown's and the teacher's care of siblings.
- The relationships with the other families in LH.
- The physiotherapist's care of the child and parents.
- The opportunity to talk and act in connection to baptism, belief and meaning.
- The physical environment.

Discussion and conclusion

The results showed that a hospice stay improved the QoL, life stability and everyday life of the whole family, but there were possibilities for improvement. This and other international studies (5) show that respite-care is important in PPC. However, this study highlighted that the professionals had difficulties balancing respite-care vs expectations that the parents should care for their own ill child. In LH there was ongoing reflection and discussion between professionals about the palliative approach of relief vs the paediatric approach with roots in developmental psychology. In PPC it is important to use knowledge from both fields to support the QoL of the whole family, regardless of the different viewpoints. The siblings were very pleased with their relations to the volunteers, the teacher and the hospice clown. However, the parents missed help to handle the siblings' reactions, questions and grief, which highlighted the need for the development of a specific sibling programme.

References

1. Jarlbæk, L. (2017). Dødssted og dødsårsager for børn og unge under 19 år i Danmark, 2012-2014. København: REHPA – Videncenter for Rehabilitering og Palliation, Klinisk Institut, SDU.
2. Zachariae, B. (2016). Livskvalitet. I: Bruun Jensen, B., Grønbæk, M. & Reventlow, S. (red.). Forebyggende sundhedsarbejde. København: Munksgaard.
3. Schutz, A. (1975). Hverdagslivets sociologi : en tekstsamling. København: Hans Reitzels Forlag.
4. Kvale, S. & Brinkmann, S. (2009). Interview. København: Hans Reitzels Forlag.
5. Raunkjær, M. (2015). Palliativ indsats til familier med børn og unge med livsbegrænsende eller livstruende tilstande – et litteraturstudie. København: PAVI, Videncenter for Rehabilitering og Palliation, Statens Institut for Folkesundhed, Syddansk Universitet.

