Information to children as next of kin in radiation departments in Norway, is it good enough?

A project by Ålesund Hospital HMR and Oslo University Hospital, Radiumhospitalet and Ullevål.

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In Norway:

- 200,000 children are the next of kin to patients with severe somatic disease. A study done by several hospitals in Norway has concluded that children need more facilitated information.*

- In 2015, there was published a book; *The helpful rays*. The book was meant to help children handle cancer in their family.

* Akershus University hospital HF et.al. (2015) *Children as next of kin – results from a multicenter study*
The Helpful Rays – Cancer cells
The Helpful Rays

Different blood cells

Different professions they will meet in a hospital

Why do they need markings on their skin

Side-effects like losing their hair

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The Helpful Rays - treatment
Purpose

- To find out if *The helpful rays* can help parents to talk to their children
- To implement the use of *The helpful rays*
Methods

- Quantitative method, questionnaire
- Possibilities to elaborate with comments
- Patients receiving radiation therapy with the custody of children that are under the age of 18,
- September 1\textsuperscript{st} 2016 and January 1\textsuperscript{st} 2017.
Do you think others in your situation can have benefits from using this book?

Yes: 97%
No answer: 3%

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Results

- 40 respondents (31 curative, 9 palliative, 2 grandparents)
- 72 children involved as next of kin
- 9 questions
How pleased are you with the information about radiation therapy given to your child/children as next of kin?

**Satisfaction**

- **Very unsatisfied**: 0%
- **Unsatisfied**: 12%
- **Satisfied**: 22%
- **Very satisfied**: 23%
- **Extremely satisfied**: 35%
- **No answer**: 8%

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To which degree has the book helped to talk about subjects as:

- The radiation treatment
- The Cancer diagnose
- Existential questions
- Feelings

Or in conversations with:

- Family
- Friends/School
The Radiation treatment

- No help 1: 22%
- 2: 13%
- 3: 10%
- 4: 10%
- Very helpful 5: 43%
- No answer: 2%

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The cancer

- No help 1: 22%
- 2: 18%
- 3: 15%
- 4: 7%
- Very helpful 5: 10%
- No answer: 28%

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Existential questions

Feelings

In conversation with family

In conversation with friends/school

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How about age differences?

This book was too advanced for my youngsters. They got more scared of the information, because it was too difficult to understand.

Parent of 3 and 5 year-old

My grandchild is 11 years old, and has been worried, and have asked a lot of questions. The book including pictures I took of the radiation machine, made it easier to talk about the cancer. My 4 year-old granddaughter understood a lot when she looked at the pictures in the book.

Grandparent of 4, 5, 8, 11 and 12 year-old

Constructive and easy explanation, even for us adults who read the book to the children. When you haven’t been treated with radiation before, you don’t know anything about this subject.

Parent of 5- and 10 year-old

We have talked about this before we got the book. The book is too childish for a 13-year-old.

Parent of 13- and 15 year-old

A unique book for young and old, child and adult. My kids and I have learned a lot, and you get guided through the subject in a way that is both good and educational.

Parent of 8- and 15 year-old
Age and satisfaction

- 2-4 years
- 5-10 years
- 11-14 years
- over 15 years

Extremely satisfied
Very satisfied
Satisfied
Unsatisfied
Very unsatisfied

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The children at 13 and 15 year old are too old for this book. The 13 year-old has read the book, and says she needs a lot more information than the book gave her. That also regards information about chemotherapy.

Parent of 13- and 15 year-old

Our youth was not interested in reading such a childish book. Maybe one needs more customized information to youths.

Parent of 15 year-old

Simple and good explanation, even for a child who perhaps is older than the target group.

Parent of 13 year-old

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Curative/Palliative

The Radiation treatment

The Cancer

Existencial questions

Feelings

In conversation with family

In conversations with friends/school

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Discussion

• No possibility to answer separate for those who have more than one child

• Similar study

• Foreigners who didn’t speak Norwegian were not included
Conclusion

• We will recommend the book because it obviously help a lot of children, and 39/40 respondents think it would benefit others in their situation.
From the husband of a 45 year-old lady with incurable cancer, with children at 8 and 15 years

We have lent the book to our 8 year-olds school, and they have read it out loud to the whole class. Their experience were very positive. The teacher had to divide the students into smaller groups to cope with all of their questions.

The junior high also wanted to lend the book.

The book is remarkable, and opens doors which gives children and adults a simple and illustrative introduction to radiation therapy and cancer.
Litterature

• Akershus University Hospital et.al. (2015) *Children as next of kin – Results from a multicenter Study*, Helsedirektoratet

Thank you for your attention!